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# "The God of all comfort:" Experiences from a biblically-based perinatal loss support group

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**“The God of all comfort”: Experiences from a biblically-based  
perinatal loss support group.**

by

**Teske Renee Drake**

A dissertation submitted to the graduate faculty  
in partial fulfillment of the requirements for the degree of

DOCTOR OF PHILOSOPHY

Major: Human Development and Family Studies

Program of Study Committee:  
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Ames, Iowa

2010

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## ABSTRACT

Perinatal loss, the loss of a baby during pregnancy, through stillbirth, or neonatal death, often goes unrecognized in society (Cacciatore, 2009; Corr, 1998; Kish & Holder, 1996). Still, it is estimated that one in five pregnancies end in miscarriage (Brier, 2008), there are over 26,000 stillbirths each year in the U.S. and the neonatal death rate is 6.8 per every 1,000 live births (Centers for Disease Control and Prevention, 2003). Despite the prevalence of such loss, women report feeling isolated through such experiences (Cacciatore, 2009; St John, Cooke, & Goopy, 2006). The purpose of this critical ethnography is to explore the support experiences of bereaved mothers who participate in the *Mommies with Hope*, a biblically-based perinatal loss support group. Viewing perinatal loss as a disenfranchised grief, this qualitative study aims to break the silence that surrounds women's perinatal loss experiences and offer validation. Through participant observations, individual interviews, and focus groups, I uncover how women experience support through *Mommies with Hope*, offering implications for research and praxis.

## CHAPTER 1. INTRODUCTION

### *Rationale*

The process of grief is a continuous journey for the bereaved, particularly for parents who have lost a child. The loss of a child does not agree with most people's perceptions of the natural order of life and death and also marks an end to the hopes and goals that parents have made for their children (Znoj & Keller, 2002). Rando and colleagues (1986) characterize parental grief as being a long lasting, severe, and complicated form of grief and the symptoms associated with it tend to fluctuate over time. When transitioning into parenthood, attachment to the child occurs antenatally, or during pregnancy. Issues of attachment will be discussed in further detail in the literature review of this study, but it is significant to point out that because parents can become attached to their unborn child before the child is physically born, that a loss during pregnancy or shortly after birth can elicit very intense grief reactions (Rhigetti, Dell'Avanzo, Grigio, & Nicolini, 2005).

It is also important for others to acknowledge the life and death of that child so that parents do not feel isolated in their grief experience or as if their loss goes unrecognized (Kish & Holder, 1996). Often in the case of perinatal loss, which for the purposes of this study can be defined as the death of an infant through miscarriage, stillbirth, or up to one month after birth, society tends to minimize the accompanying grief. With the diminishing of such a significant loss, parents become disenfranchised in their grief and bereavement (Doka, 1989). By examining the experience of perinatal loss as a form of disenfranchised grief, this study uncovers the support experiences of women who have suffered from perinatal loss, specifically through their involvement in a support group, *Mommies with Hope*.



### *Purpose Statement & Research Questions*

The purpose of this critical ethnography is to explore the support experiences of mothers who participate in the *Mommies with Hope* support group. *Mommies with Hope* is a biblically-based support group for mothers who have experienced perinatal loss. Perinatal loss is defined as the loss of a child during pregnancy or up to one month after birth. Acknowledging and framing the phenomenon of perinatal loss as a form of disenfranchised grief and bereavement, I aim to understand how mothers view and receive support through participation in the *Mommies with Hope* support group as well as understand how participation in the group validates these women's preinatal loss experiences.

The questions of this research are: How do mothers experience support through participation in the *Mommies with Hope* support group? How does the group help or hinder mothers' bereavement support experiences? How does participation in the group validate mothers' experiences with perinatal loss?

### *Organization of the Study*

This study incorporates several topics, including the topics of perinatal loss as a disenfranchised grief, perinatal bereavement, and supports for women experiencing perinatal loss. The issues of spirituality as a source of support are central in this research, as participants in this study attend the *Mommies with Hope* support group, a biblically-based group for women who have experienced the death of a child.

Chapter 2 of this study provides a review of relevant literature on the topics of perinatal loss, bereavement, and support. I define three types of perinatal loss incorporated in this study, and then provide a basis of understanding the significance of such loss by examining literature on the topic of antenatal attachment. I then discuss the literature on

perinatal bereavement as a form of disenfranchised grief, lacking recognition in society. In summary, I examine the supports available to women who have experienced perinatal loss and specifically discuss spirituality as a source of support for the bereaved.

In Chapter 3, I start by sharing my researcher positionality statement, acknowledging the experiences and biases I have with the topic under investigation. I also detail critical theory, which informs my methodology, study design, and analysis. In conducting a critical ethnography, I seek to understand how mothers experience support through the *Mommies with Hope* support group. With a focus on marginalized groups of people or “cultures,” critical ethnography assists in my desire to bring attention to women’s experiences with perinatal loss. I have included some elements of autoethnography in this study, which is discussed in Chapter 3 as well. I also provide a rationale for the methodology and give details pertaining to the participants, procedures of data collection, and the process of analysis. Further, I address issues of trustworthiness and rigor, as well as ethical considerations in Chapter 3.

Chapter 4 details the findings, discussion and limitations of the current study. I share a table to indicate how the findings address the questions of this research and also share a figure that displays the findings in a visual format. Findings include three encompassing themes: 1) Our Hope Stories: Linked by Loss, 2) The Silence is Broken, and 3) *Mommies with Hope: A Safe Haven*. The sub-themes that emerged from this study include: 1) Receive Support over Time, 2) Experience Validation, 3) Build Friendship, 4) Foster Spirituality, and 5) Able to Help Others. Finally, the discussion connects the findings from this study to the relevant literature. I address the limitations of this research in this chapter as well.

The concluding chapter, Chapter 5, provides a summary of the study, concluding remarks, and implications for future research and praxis. An emphasis of critical ethnography includes the emancipatory and action-oriented facets of doing such research, which will be addressed in this section. Finally, I conclude the study with a section that details a personal reflection on the study as a whole.

An important aspect of this study to take note of is my very personal connection to the topic under investigation and the inclusion of autoethnographic elements to this study. My personal experience with the death of my daughter, Chloe, due to lethal prenatal diagnosis of a chromosomal abnormality, is part of what generated the establishment of *Mommies with Hope* as well as my interest in researching topics related to perinatal loss. Thus, the entire study is filtered through my interpretation, both as a researcher, co-founder/facilitator of *Mommies with Hope*, and as a bereaved mother. Furthermore, I experienced two miscarriages during the process of data collection and analysis for this study, the impact of which is addressed particularly in Chapter 3 of this study.

## CHAPTER 2. LITERATURE REVIEW

### *Perinatal Loss Defined*

Perinatal loss can be defined as the loss of an infant as a result of miscarriage, stillbirth, or neonatal death (Robinson, Baker, & Nakerud, 1999). According to Malacrida's (1997) expansion of this definition, perinatal loss includes the infant death as a result of complications during pregnancy, premature birth, stillbirth, or complications resulting in death during the first month of life. For the purposes of this study, I will be focusing on the three types of perinatal loss mentioned above, including a) miscarriage, b) stillbirth, c) neonatal death. This section will define and differentiate the prevalence of each of these various types of perinatal loss.

### *Miscarriage*

Miscarriage is defined as pregnancy loss prior to 20 weeks gestation. More specifically, Cacciatore and colleagues define miscarriage as, "the spontaneous termination of a pregnancy resulting from natural causes before the fetus is viable outside of the mother, generally before 20 weeks gestation" (Cacciatore, DeFrain, & Jones, 2008, p. 443). It is estimated that nearly 20% of all known pregnancies end in miscarriage (Brier, 2008; Gross, 2008; Robinson, et al. 1999). The key word here is "known" as some women likely experience miscarriage before they even know they are pregnant, so the rates are expected to be higher. Given these statistics, it is evident that thousands of parents experience perinatal loss each year.

### *Stillbirth*

Stillbirth is defined as "fetal death occurring between the twentieth week of gestation and the time of birth, resulting in the delivery of a dead child" (DeSpelder & Strickland,

2009, p. 389). In the United States, over 26,000 women experience a stillbirth each year. Stillbirth occurs ten times more frequently than SIDS (Sudden Infant Death Syndrome). Approximately one in 110 pregnancies will result in stillbirth (Cacciatore, 2009). In nearly half of all stillbirths, the cause of death is not able to be determined (Froen, Arnestad, Frey, Vege, Saugstad, & Stray-Pederson, 2001). In recent years, advocates have worked to enact legislation dealing with the vital records of stillborn babies. Previously, women were denied any certificate of birth. To date, about half of all U.S. states issue a certificate of birth resulting in stillbirth (Cacciatore, 2009).

#### *Neonatal Death*

Neonatal death is the death of an infant during the neonatal period, or within four weeks after birth (DeSpelder & Strickland, 2008). Approximately 1% of all U.S. births result in perinatal loss. More children die just before birth or during the neonatal period than at any other period during childhood (Sumner, Kavanaugh, & Moro, 2006). In fact, two-thirds of all infants that die, die during the neonatal period, or the first month of life (Romesberg, 2004). According to the Centers for Disease Control and Prevention (2003), neonatal deaths, or deaths within the first month of life, occur at a rate of 6.8 per every 1,000 live births. Congenital anomalies, comprising .5-1% of all births, or between 30 and 50 thousand births, are the leading cause of these infant deaths each year in the U.S. (Calhoun, Reitman, & Hoeldtke, 1997; Hoeldtke & Calhoun, 2001).

#### *Antenatal Attachment and Bonding*

Antenatal attachment refers to the relationship experienced between the expectant mother and her unborn child. This relationship develops during the pregnancy and is a relationship that both mothers and fathers usually acquire (Rhigetti, et al., 2005). According

to Condon (1993), attachment can be understood in terms of the affective experiences and intensity of preoccupation. Examples of each of these concepts include the amount of time spent thinking about, talking to, dreaming about or palpating the fetus.

Another term that has been used to describe this prenatal relationship between mother and child is that of maternal-fetal attachment (MFA). According to Salisbury and colleagues, MFA is generated from the mother's cognitive portrayals of her unborn child (Salisbury, Law, LaGasse, & Lester, 2003). Nurturing, comforting, and physical preparation behaviors of the mother indicate the mother's care for and commitment to her unborn child. Examples of these types of behaviors include eating healthy and receiving timely prenatal care (nurturing), stroking her belly or talking to her unborn child (comforting), and setting up a nursery (physical preparation). It is through all of these behaviors that the mother begins to bond with her baby (Salisbury et al., 2003).

Peppers and Knapp (1980) propose nine events that occur and contribute to attachment between mother and child long before the child is born. These events are (a) planning the pregnancy, (b) confirming the pregnancy, (c) accepting the pregnancy, (d) feeling fetal movement, (e) accepting the fetus as an individual, (f) giving birth, (g) seeing the baby, (h) touching the baby, and (i) giving care to the baby (Peppers and Knapp, 1980). It is important to note that the first five of the nine events occur before the birth of the child, thereby providing support for the notion that attachment occurs prenatally. According to Kish and Holder (1996), various aspects surrounding the pregnancy serve as a way of strengthening the prenatal bond between mother and child. These activities, similar to those cited by the researchers mentioned previously, include planning for the pregnancy, seeking

out prenatal care, viewing the baby by ultrasound, and hearing his or her heartbeat (Kish & Holder, 1996).

Some argue that advancements in medical technology have encouraged antenatal attachment. Because of such advancements, many women in American society do not tend to worry about the possibility of death for their infants and therefore, begin bonding with their unborn child early on in pregnancy. In addition, the use of ultrasound as a routine procedure in prenatal care has given parents the opportunity to see their unborn child, providing a means for them to visually bond with the baby (Robinson, et al., 1999). Though the procedure is conducted with the intent to screen for various anomalies and/or birth defects, many parents see the ultrasound appointment as an opportunity to meet their child, and they often look forward to taking home a video or still image of the baby as a keepsake. According to Detraux and colleagues (1998), the process of attachment is fostered through the use of ultrasound examination because parents are given the chance to visualize their future child (Detraux, Gillot-DeVries, Vanden Eynde, Courtois, & Desmet, 1998).

According to and Page (1987), attachment occurs between mother and unborn child whether or not the pregnancy is considered high-risk or threatened. In some cases, ultrasound may provide a diagnosis of a lethal anomaly, or a diagnosis in which the unborn child is not expected to live. In these instances, parents are often confronted with two options. The first is to terminate the pregnancy and the second is to continue the pregnancy, despite the lethal diagnosis (Hoeldte & Calhoun, 2001). According to Keefe-Copoperman (2005), mothers who terminate a wanted pregnancy due to a lethal prenatal diagnosis report feelings of loss and of emptiness, often compounded by guilt over ending a life. Thus, this unique situation and subgroup of women who have experienced perinatal loss in this manner

must be considered when examining support needs of families. There is a dearth of research on parents who choose to continue such pregnancies because doing so is unique. Therefore, this unique situation, on the other end of the spectrum, must also be approached in a way in which the unique needs of these parents will be met through various bereavement support measures (Hoeldtke & Calhoun, 2001). From the evidence gathered on antenatal attachment and the bonding process of pregnant women with their unborn children, it is safe to assume that when struck by perinatal loss, the grief that accompanies such a loss is tremendous, regardless of whether the child was suspected to live long or not based on the ultrasound findings or other medical technology. The death of an unborn child would naturally elicit a grief reaction due to the antenatal attachment that takes place between parents and their unborn child (Worth, 1997).

### *Grief*

In the very broadest sense, grief is “the reaction to loss” (Despelder & Strickland, 2008, p. 312). It is complex and encompasses emotion and thoughts, as well as physical and spiritual responses (DeSpelder & Strickland, 2008). The notable work by Kubler-Ross (1969) outlines five stages of grief, including: 1) Denial, 2) Anger, 3) Bargaining, 4) Depression, and 5) Acceptance. Her original work focused on the terminally ill patient (Kulber-Ross, 1969), but many have adopted these five stages to apply to the grief of those who survive a loved one’s death. It is important to note that the stages posed above are not necessarily linear and sequential (DeSpelder & Strickland, 2008). In fact, Cacciatore and colleagues (2008) assert, “Grief often does not keep to a schedule. It is a timeless, nonlinear procession of emotions that rises and falls” (p. 452).



There are many models of grief that help provide basic understanding. DeSpelder and Strickland (2008) assert that the existence of such models can be helpful as well as harmful to the bereaved. On the one hand, they may provide a sense of solace to the bereaved who find comfort in the belief that grief has a consistent pattern or sequence. On the other hand, such models attempt to provide a simple framework for a dynamic experience, thereby altering the complex reality of grief (DeSpelder & Strickland, 2008). Other grief models to take note of, in addition to that of Kubler-Ross' (1969) mentioned above, include the Worden's (2002) "tasks of mourning" and Rando's (1993) "Six R's." In contrast to the work of Kubler-Ross, both Worden and Rando incorporate the need for the bereaved to adjust to the new relationship he/she has with the deceased person (Rando, 1993; Worden, 2002). In other words, the bereaved person must recognize and adjust to the "new normal" of life without his/her loved one. For those experiencing perinatal loss, this may be adjusting to the reality of the loss and letting go of what might have been.

While the above-mentioned models of grief provide a foundation for understanding grief in general, Rando's (1993) work on complicated mourning is particularly helpful for understanding the perinatal loss experiences of women. While it is not possible to take a checklist approach to determining whether one's grief is complicated, there are certain situations that are at greater risk for complicated mourning in the bereaved. Two of these situations cited by Rando include: 1) the death of a child, and 2) the bereaved's perceived lack of social support (DeSpelder & Strickland, 2008; Rando, 1993). The grief response of parents who have endured perinatal loss can be the same type of response as people who have lost a loved one later in life. Initially, parents report feelings of shock, disbelief, confusion, and denial (Kazak & Noll, 2004; Vance, et al., 1995; Wing et al., 2001). Parents

who have experienced the loss of a child often describe their grief as becoming different over time, rather than ever getting better, though it may lessen in intensity. Because the grief process is unique to each individual who experiences it, it could last a lifetime (Romesberg, 2004).

### *Disenfranchised Grief*

*“Whatever is disenfranchised in grief is not free to experience or to express itself. It is prohibited, tied down, not sanctioned, and not supported by society” (Corr, 1998, p. 17).*

Defined by Doka (1989), disenfranchised grief is “the grief that persons experience when they incur a loss that is not or cannot be openly acknowledged, publicly mourned, or socially supported” (p. 4). He identified three primary ways by which grief can be disenfranchised, which happens when the relationship, the loss, or the griever are not recognized (Doka, 1989). With regard to perinatal bereavement, such losses are disenfranchised because society often fails to recognize the significance of such loss (Brier, 2008; Corr, 1998; Nichols, 1989). According to Corr (1998), disenfranchisement goes beyond the guise of being unaware and suggests an active rejection of one’s bereavement experience. In other words, the disenfranchisement itself is not a simple matter of others not knowing about the loss, but is more of a disregard for the actual grief experience, based on the circumstances of the loss.

According to Corr (1998), there is always a particular social or cultural context that surrounds those who are grieving. Harris (2009) outlines four “rules” in Western society that tend to dictate responses to loss: 1) Who has permission to grieve and/or whether the relationship to the person who died is valid based on societal expectations, 2) The duration of grief, 3) The manifestation of grief, and 4) Whether or not the death has stigma attached to it.

The impact of violating these above-mentioned rules can have lasting implications for the bereaved, as Harris (2009) asserts that it is these rules that govern public policies and social support. When society holds a discounting attitude regarding a particular disenfranchised group of bereaved, the factors that typically allow for mourning are absent and support is thereby lacking (Corr, 1998). Grief is disenfranchised when it is unrecognized or unsupported by society (Corr, 1998). Thus is the case with perinatal loss situations (Cacciatore, 2009; Kish & Holder, 1996; Pesek, 2002; St John et al., 2006). The section to follow will discuss perinatal bereavement, focusing on aspects of ambiguity and silence, each of which contribute to the disenfranchisement of women who have experienced perinatal loss.

#### *Perinatal Bereavement: Ambiguity and Silence*

Kazak and Noll (2004) suggest that the death of a child is one of the “most horrifying events that adults can imagine” (p. 219). One of the most stressful events that an adult can experience is the death of a child (Wing, Clance, Burge-Callaway, & Armistad, 2001). As reported by Wing and colleagues (2001), the death of a child triggered more intense grief reactions for parents than did the death of those individuals’ spouse or parent.

Particularly with the death of an infant, the loss is accompanied by a number of secondary losses, including the loss of the hopes and dreams that the parents imagined for their child (Wallerstedt et al., 2003; Wing et. al., 2001). According to Wallerstedt and colleagues (2003), perinatal loss is unique and complex in that it involves a loss of self, few memories to use as way of mourning, a sense of biologic failure, and minimization by others. In coping with a significant loss, memory sharing with others plays a crucial role in the resolution of grief. Perinatal loss, however, typically lacks many memories, thereby

complicating the grieving process (Kish & Holder, 1996). Parents have described the moving on stage of grief regarding perinatal loss as “reconciliation and recovery” rather than using the term “resolution” because it is something that is never truly resolved (Romesberg, 2004, p. 163). The lack of recognition and discounting attitude of society often leaves the parents feeling isolated and distraught, when they were likely anticipating their birth experience to be accompanied by feelings of joy (Bennet, et al., 2005).

The ground-breaking work of Pauline Boss (1999) on ambiguous loss is key to providing an understanding perinatal loss as a form of disenfranchised grief. According to Boss (2001), when a family member’s presence or absence in the family is ambiguous, the situation can be referred to as ambiguous loss. Thus is the case in perinatal loss situations. Cacciatore and colleagues (2008) assert that children who are stillborn are often not acknowledged by others as a member of the family. This lack of clarity surrounding family membership by others clearly determines that perinatal loss is an ambiguous loss.

Cacciatore and colleagues (2008), use Boss’ framework of ambiguous loss for understanding the phenomenon of stillbirth in a recent study. They assert, “family members’ profound feelings of grief and ambiguous loss are borne in a social environment that denies this reality because the child’s death was invisible to most of the world” (Cacciatore, DeFrain, & Jones, 2008, p. 440). Recognizing that stillbirth, in addition to other types of perinatal loss, are often seen as “invisible deaths” supports the view that each of these experiences are, in fact, disenfranchised in society.

One aspect of this disenfranchisement includes the silence that surrounds perinatal loss experiences. In a qualitative study by St John and colleagues (2006), they aimed the give voice to women’s perinatal loss experiences (St John, Cooke, & Goopy, 2006). They

assert, “While society relishes birth, there is a silent disregard for the grief and despair that pregnancy loss evokes” (St John et al., 2006, p. 8). Other researchers (Cacciatore, 2009; Layne, 2003) agree that perinatal loss is generally devalued in society, contributing to the silence experienced by women who endure such loss. In a study by Harvey and colleagues (2001) on miscarriage, they found that silence, loneliness, and isolation are common among women (Harvey, Moyle, & Creedy, 2001). St John and colleagues found that women were silenced in their perinatal loss experiences by hiding the experience in fear of rejection from others. In turn, they were left feeling isolated. Isolation and silence was exacerbated by the uncomfortable response by family and friends who failed to acknowledge the child who died or the woman’s role as a mother (St John et al., 2006).

#### *Perinatal Loss Supports*

The lack of social support for parents who have experienced perinatal loss can have an impact on the way they experience grief (Bennett, Lee, Litz, & Maguen, 2005). Since the 1970’s social support has been linked to positive health outcomes as well as to the prevention of disease (Hutti, 2005). According to Ginsburg and Rapp (1991), social support is vital both during and after childbirth, regardless of the outcome. Logsdon (2000) asserts that the social support offered must meet the needs of the grieving parents in order to be effective. It should also be offered by a preferred provider, such as family members or close friends. If this is not possible, the person in need of such support may decide to leave his or her needs unmet (Logsdon, 2000). Lang and colleagues (2004) suggest that a perceived lack of support can jeopardize the health of those needing support and affect the entire experience for them (Lang et. al, 2004).

Distinguishing from social support, professional support includes support that comes

from healthcare or mental health providers. This kind of support includes various counseling interventions, organized support groups, teaching, or encouragement (Hutti, 2005). Logsdon (2000) suggests that, like social support, professional support can also result in improved health outcomes. Lack of support can increase the likelihood of adverse health effects and the physical symptoms associated with grief by more than 60% (Romesberg, 2004). Hutti (2005) suggests that support is most credible to bereaved parents when it comes from a person who has had a similar experience and has managed to deal with the situation effectively. A widely known program used as a means of professional support in many hospitals across the United States is Resolve Through Sharing (RTS). RTS is a program that provides nurses with training on perinatal and neonatal loss, offers support to families who experience such loss, and also provides families with mementos of their baby (Romesberg, 2004). Mementos of the baby are believed to be extremely helpful for parents throughout the grieving process and can include items such as photos, hand and foot prints, or a lock of hair (Hutti, 2005). Information on community resources should also be made available to families so that they have the opportunity to make connections with others who have experienced a similar loss, as local communities may offer a variety of support services (Hutti, 2005). Regardless of the availability, however, Cacciatore and colleagues (2009) found that one of the most important aspects of support is that women perceive that such support exists (Cacciatore, Schnebly, & Froen, 2009).

Family and close friends tend to minimize the grief experience of the couple in an effort to provide social support. Unless they too have experienced perinatal loss, they often do not understand the intensity of the parents' grief over a child they never had the chance to get to know (Kish & Holder, 1996; Wing, et al., 2001). Such minimization only serves to

silence those who have experienced perinatal loss. Redlinger-Grosse and colleagues (2002) found that many parents they interviewed about their experience with perinatal loss due to a diagnosis of holoprosencephaly felt unsupported by family or friends. In some cases, family members questioned their decision of expectant management of their pregnancy (Redlinger-Grosse, Bernhardt, Berg, Muenke, & Biesecker, 2002). Although well-meaning, family and friends tend to offer hurtful clichés like, “You can always have another baby” or “At least you didn’t bring the baby home,” as support or encouragement, which subsequently minimizes the loss of the child that recently died and fails to acknowledge that child’s life (Kish and Holder, 1996, p. 76). The length of time that the parents spend with the child should not serve as an indicator for how significant the loss of their child is to them. Rather, all of the complex elements of attachment should be taken into account, thereby recognizing the death of their child, whatever the age, as a significant loss (Robinson, et al., 1999).

### *Support Groups*

A number of considerations must be taken into account when designing and implementing supportive programming for bereaved parents due to varying factors and the numerous complexities that influence perinatal bereavement. The death of an infant, whether due to miscarriage, stillbirth, or neonatal death, is a tragic and senseless occurrence in which parents experience a very intense grief reaction. Each person’s experience is unique. Hutti (2005) suggests that healthcare providers refrain from using a “cookbook” approach when providing support to those who have experienced perinatal loss. Rather, each family should be assessed individually and offered supportive services that meet their specific needs (Hutti, 2005). For instance, significant gender differences have been established in the literature, indicating a need to tailor support services to meet the unique needs of both mothers and

fathers. Similarly, women are reported to place greater importance on support groups after loss than their male counterparts (Cacciatore et al., 2009). Admittedly, additional research must be conducted in order to obtain an accurate portrayal of fathers' grief surrounding perinatal loss so that we can begin to understand how his needs may differ from his partner's needs. Again, assessing on an individual basis is key when providing support to meet the bereaved parents' needs.

Regarding support groups, in particular, Pesek (2002), support groups can be especially effective for groups of individuals who are disenfranchised in their grief experiences. The support group setting gives the disenfranchised griever an opportunity to "obtain recognition, understanding, and support" (Pesek, 2002). Glanz and colleagues (2002) outline four types of support for the griever in a support group setting: 1) Affiliation or emotional support, 2) Instrumental support, 3) Informational Support, and 4) Appraisal (Glanz, Rimer, & Lewis, 2002). The first, affiliative or emotional, instills in the griever a sense of belonging and acceptance. The second, instrumental, provides a safe place for discussion while the third type, informational, offers practical assistance. Finally, the fourth type, appraisal, helps normalize the grief experience (Ganz, et al., 2002). This can be particularly helpful for those bereaved by perinatal loss.

In a mixed methods study by Cacciatore (2007), findings suggest women who attended a perinatal loss support group had fewer posttraumatic stress symptoms than their non-attending counterparts. Qualitative findings from this study indicated that when women were connected with others who have had a similar loss experience, psychological outcomes were reduced (Cacciatore, 2007). Similarly, when investigating social support after perinatal loss, Kavanaugh and colleagues (2007) found that women found it most helpful to have



someone to talk to who had been through a similar experience, most typically another bereaved mother (Kavanaugh, Trier, Korzec, 2007). With regard to support groups, Cacciatore asserts “This connection between two or more human beings reduces feelings of disenfranchisement, isolation, and helps the mourner create and recreate meanings in their experiences” (Cacciatore, 2007).

### *Spirituality as a Source of Support*

When a person experiences loss, they may question their own religious and spiritual understandings (Tedeschi & Calhoun, 2006). For the purposes of this paper, it is necessary to operationally define the concepts of religion and spirituality. According to Koenig and colleagues (2001), religion is broadly referred to as an “organized group and shared beliefs.” In contrast, spirituality is more of a focus on the individual’s personal belief system (Keonig, McCullough, & Larson, 2001). More specifically, Tedeschi and Calhoun (2006) define religion as “a component of the worldview that includes supernatural elements, beliefs that, at least in part, address issues of life’s purpose, how life should be lived, and what happens after biological death.” (p. 106). They go on to describe religion as being characterized by “corporate entities, with either explicitly stated creeds or a generally shared set of assumptions about transcendent realities” (Tedeschi & Calhoun, 2006, p. 106). Spirituality, however, does not necessitate shared beliefs or structured organizations (Tedeschi & Calhoun, 2006).

Understanding the distinction between religion and spirituality is important with regard to the current study, as each of these terms is relevant to the *Mommies with Hope* support group. Considering the fact that *Mommies with Hope* is an Evangelical Christian support group, it is apparent that we identify with the Christian religion. That being said,

there are many Christian denominations in existence and going into such a discussion is beyond the scope of this paper. I mention this, however, because it is essential to understand the core religious beliefs of *Mommies with Hope*, as it serves as a basis for the provision of bereavement support to mothers who have experienced perinatal loss support. Please see the *Mommies with Hope* Faith Statement (appendix A) for an in-depth description of our core religious beliefs.

Often the first place a grieving individual turns to for comfort and support is a faith group or religious congregation (Doka, 2002). In a study by Walsh and colleagues (2002), they found that the strength of one's spiritual beliefs was an important predictor for bereavement outcomes. More specifically those who reported having strong spiritual beliefs indicated a linear progression of recovery from loss, as opposed to those with low or no strength of beliefs, who showed little change nine months after loss, or temporary gain then intensified grief, respectively (Walsh, Kiri, King, Jones, Tookman, & Blizard, 2002).

With regard to bereaved parents, Marrone (1999) contends that the parents often face a profound psychospiritual transformation as they adjust and cope with their loss. Klass (1999) supports this notion in his assertion that such a transformation is integral to bereaved parents' healing process. Still, for others, the death of a child may cause them to turn away from previously held religious beliefs due to embitterment (Marrone, 1999). Other researchers (Cait, 2004; Tedeschi & Calhoun, 2004) state that questioning why a particular loss occurred can also lead people to rejecting or strengthening their religious beliefs. Whichever the situation, it has been established in the literature that spirituality/religion plays a role in coping with loss. This issue applies to the current study given the Christian nature of the *Mommies with Hope* support group by which women are receiving support.

### CHAPTER 3. METHODOLOGY

#### *Researcher Positionality*

According to Madison (2005), “Positionality is vital because it forces us to acknowledge our own power, privilege, and biases just as we are denouncing the power structures that surround our subjects” (p. 7). With regard to my own positionality, I initially approached this research with a personal experience of lethal prenatal diagnosis and perinatal loss of my second child, Chloe, in 2006. This experience played a major role in a shifting in my own spiritual beliefs and growth. It is through this lens I intended to interpret the findings by conducting this critical ethnography. During the research process, however, I experienced loss, yet again. This time it was two separate miscarriages; the first occurring at six weeks gestation, the second at nearly 14 weeks gestation. Both of the miscarriages occurred during data collection and analysis of the current study.

Throughout and since the birth and death of Chloe, in particular, I relied heavily on my faith in God. During my work on my thesis research in 2007 – 2008, which occurred simultaneous to this time of spiritual growth in my life, I partnered up with a fellow bereaved mother, Jen, who had been through a similar situation as I and who was one of the participants in my thesis study. We shared a mutual passion and felt a calling to develop a biblically-based support group for other “mommies.” She had experienced the loss of her baby boy, Andrew Lindsay, at 21 weeks gestation, after choosing to induce early upon finding out that her son had not developed any kidneys, a condition that was incompatible with life. We held the same Christian beliefs and each experienced our faith as a true source of comfort, support, and encouragement through our grief journey. We wanted to share and offer similar support to other mothers impacted by the loss of a child. Thus, after our first

time officially meeting, we had a group name and logo and were in the process of planning our next time to meet, where we would officially start the planning for our first *Mommies with Hope* support group meeting.

With regard to positionality, Madison (2005) asserts that “critical ethnography is always a meeting of multiple sides in an encounter with and among the Other(s), one in which there is negotiation and dialogue toward substantial and viable meanings that make a difference in the Other’s world” (p. 9). Thus, this study will be interpreted as such, examining the complexities that exist among relationships between myself as researcher, support group facilitator, bereaved mother and self-proclaimed born-again Evangelical Christian and the broader society in which we live, where all too often perinatal loss goes unacknowledged, seems insignificant, and is often secretly and silently experienced.

The issue of silence surrounding perinatal loss was one that I, personally, did not fully realize until I experienced miscarriage firsthand. This occurred three years after my daughter, Chloe’s birth and death. In the midst of conducting this study, I have had two miscarriages, as previously mentioned. With Chloe, I was visibly pregnant and gave birth to a baby who weighed 3 pounds, 6 ounces and fit into preemie size clothing. We took pictures, received hand and footprints, cut a lock of her hair. These tangible mementos made her existence real. With the miscarriages, however, I struggled with whether or not to tell anyone and if so, what to say. In response to this personal turmoil over being silenced in my own loss, I reluctantly, yet boldly wrote a post on the *Mommies with Hope* blog, just one week after my first miscarriage at six weeks along, titled “To Not Be Silenced.” The aim of this very post was to encourage women “to not be silenced” in their loss and acknowledge

the valuable and precious life of their child, even if that baby was “just 6 weeks along.” Here is an excerpt from that post:

“As I sit to write this post, I am a different woman than who I was just over a week ago. Early last week, I would have told you that I am the mother of three precious children, two of whom are playing amongst scattered toys on the floor as I write, and one whom resides in the dwelling place of our Lord. I would have also told you that I was eagerly anticipating the birth of our fourth child, but to keep it quiet because we hadn't told hardly anyone and were waiting for the right moment to spread this exciting news. I may have even shared with you that I was nervous about this pregnancy, which is to be expected considering how Chloe's loss impacted our life and made us all too familiar with the reality that babies, yes even babies, can die an untimely death. Sadly, I cannot tell you those things above today. In this past week, my story has changed in what seems to be the blink of an eye...Last week I may have been able to share with you the "secret" that child number four was on the way, but today, that child is cradled in the loving arms of Jesus with a big sister, named Chloe, singing sweet lullabies amidst the angels nearby. I will admit, I struggled with whether or not to share this experience with you all. Oh, to not be silenced! I've had the lies of the enemy tormenting me, saying, ‘You were *only* six weeks along.’” True. I was six weeks along. And in those weeks, there was a longing, an anticipation, and a joyful excitement about the blessing of this child...I love that sweet baby...I know that I am not alone and that there are many of you who have had to walk these unfortunate footsteps before me. While I can never imagine what you specifically and uniquely experienced, I can say to you that I know it hurts. I do not know exactly how

you feel, but I can empathize. Even after having experienced the loss of Chloe, it is a different child, a different grief, a different experience. No two losses are the same, nor can they be compared. Still, it is a loss and we grieve, regardless of what the enemy or the world is whispering in your ear. In John 16:33, Jesus says, 'I have told you these things, so that in me you may have peace. In this world you will have trouble. But take heart! I have overcome the world.' The world, in all of its ugliness, will fail us over and over again. We will hear senseless comments, receive well-intentioned, yet hurtful words, and will likely wonder whether it would have been best to keep quiet about the whole thing in the first place. I've wrestled with this all week, wondering *if* I should tell, *who* I should tell, and what I should say. My conclusion...to not be silenced! If you are in this place today, tempted by the world to devalue the life of your child, wondering whether that precious baby's life was significant, it is my prayer that you find comfort in these truths: You loved your child. Your child's life mattered. God loves your child. Your child is with God. Your child's life, no matter how brief, has a purpose. So ladies...Do not be silenced."

*(Self, Mommy to Chloe, Baby D., and Riyah)*

### *Purpose Statement & Research Questions*

The purpose of this critical ethnography is to explore the support experiences of mothers who participate in the *Mommies with Hope* support group. *Mommies with Hope* is a biblically-based support group for mothers who have experienced perinatal loss. Perinatal loss is defined as the loss of a child during pregnancy or up to one month after birth. Acknowledging and framing the phenomenon of perinatal loss as a form of disenfranchised

grief and bereavement, I aim to understand how mothers experience support through participation in the *Mommies with Hope* support group.

The questions of this research are: How do mothers experience support for their perinatal loss experiences by participating in the *Mommies with Hope* support group? How does the group help or hinder mothers' bereavement support experiences? How does participation in the group validate mothers' experiences with perinatal loss?

### *Critical Theory*

Historically, critical theory originates with the Frankfurt School, which was comprised of notable figures such as Horkheimer, Adorno, and Marcuse, as well as others (Prasad, 2005). They had goals to go beyond their systematic forms of critiquing social conditions and saw the need to take action to better the world (Kincheloe & McLaren, 1994). Jurgen Habermas, a German philosopher, continued and built upon the initial Frankfurt Schools' theoretical contributions in his work in communication theory (Prasad, 2005). For Habermas, theory serves the purpose of human action. As such, this means a greater human freedom (Crotty, 2003).

Three principles of critical theory include: 1) knowledge and understanding are rooted in their historical context, 2) social critique is taken into account, and 3) emancipation is key (Lunn, 2010). With regard to the current study, I am addressing each of these three principals by presenting the current state of perinatal loss supports, viewing it through a critical lens and recognizing perinatal loss as a disenfranchised grief, and working toward praxis of the findings to liberate women from experiencing their grief in silence and isolation. According to Kincheloe and McLaren (2002),

“A critical social theory is concerned in particular with issues of power and justice and the ways that the economy; matters of race, class, and gender; ideologies; discourses; education; religion and other social institutions; and cultural dynamics interact to construct a social system” (p. 90).

A critical approach is concerned with aspects of emancipation and change. With regard to this study, the injustice is in how society views perinatal loss. Supports to women are lacking, in part, because of the silent nature of such loss. In viewing perinatal loss as a disenfranchised grief and conducting this study in such a light, implications for praxis will aid in taking steps toward challenging this injustice.

### *Critical Ethnography*

Madison (2005) describes critical ethnography as a way in which to challenge injustices or unfairness within a specific lived domain. From a criticalist standpoint, society is inequitable and inquiry ought to be directed toward making positive transformations in society (Carspecken, 1996). The critical ethnographer is compelled to conduct research that will make a change in whatever the conditions are that are creating or allowing inequity (Madison, 2005). As previously stated, perinatal loss often goes unrecognized in society (Kish & Holder, 1996). Parents are not afforded acknowledgement for their loss, as is prevalent with other types of loss (Keefe-Cooperman, 2005). A critical approach aids in working toward a praxis for bereavement support through the *Mommies with Hope* support group while also offering implications for the development and implementation of support through other means, as will be discussed in the Implications section of this proposal. In the words of Thomas (1993), critical ethnography is “conventional ethnography with a political purpose” (p.4). In other words, critical ethnography goes beyond the descriptive or



explanatory and uses knowledge gained as a contribution to social change, toward advocacy, and to reach emancipatory goals (Madison, 2005; Thomas, 1993), each of which will be addressed in the current study, particularly in Chapter 5, Conclusions.

According to Crotty (2005), critical inquiry is a cyclical process. It does not consist of research and conclude with action. Rather, it is an ongoing process of reflection and action whereby our actions cause change, compelling us to revisit and critique our initial ideas again (Crotty, 2005; O'Reilly, 2005). Thus is the case in the current study. With each new understanding uncovered throughout the research process and throughout simultaneous data collection and analysis procedures, it became necessary for me to continuously reflect and critique the data, my analytic interpretations, and my continued attention to the issues. This process of simultaneous data collection and analysis is discussed more thoroughly in the Analysis section of this chapter.

### *Elements of Autoethnography*

When I set out to conduct this study, I did not intend to incorporate elements of autoethnography. As the study progressed, however, I began to wrestle with the fact that I had experienced two miscarriages during the time in which I was actively collecting and analyzing data. These losses were fresh and undoubtedly impacted who I was as a woman, mother, support group facilitator, and researcher. Cognizant of these complexities, coupled with encouragement from a mentor and colleague, I knew that the study was no longer what I initially set out for it to be. It was still a critical ethnography, complete with the integration of elements of autoethnography.

Ellis and Bochner (2000) refer to autoethnography as “an autobiographical genre of writing and research that displays multiple layers of consciousness, connecting the personal

to the cultural” (p. 733). Although the current study is not an autoethnography in its own right, there are elements of autoethnography woven into the way in which I came to analyze and interpret the data and present the findings. According to Anderson (2009), qualitative research has always included some element of autoethnography. For a study to be autoethnographic, the investigator must be a complete member of the culture or group under study (Anderson, 2009). Pertaining to the current study, I embarked on this research having full member status of the “culture” I intended to study. Participants were to be women who have experienced loss that were currently participating in the *Mommies with Hope* support group. Though I facilitate the group, the support is mutual. I knew this already in my experience of losing Chloe, nearly four years ago, but came to truly experience this mutuality of support on a much deeper level during the process of this research, as I experienced two more losses: both miscarriages. While I was researching the phenomenon at hand, I was also “purposively engaging in it” (Anderson, 2009, p. 380).

Humphreys (2005) asserts that the use of autoethnography adds value to qualitative research and serves to enhance the study by way of reflexivity of the methodology. This is precisely why I knew it was fitting for me to incorporate more of myself into the study as the research progressed. While I did not set out to complete this study with elements of autoethnography in mind, my life circumstances led me to that place when I had the miscarriages. In order to be transparent throughout the research process, more of me and what I was going through had to come into light. Although I do not consider myself a full participant in this study, I do incorporate elements of autoethnography in the research process by being a visible actor within the study and inserting my own feelings and experiences (Anderson, 2009) to help portray the phenomenon under study. I have done so by including

an artifact, which includes excerpts of blog posts I have written about my loss experiences, as well as the way in which I have written up the findings in Chapter 4. While I have made use of some elements of autoethnography in the write up of this study, I have not conducted an autoethnographic analysis. Rather, autoethnography has lent me a particular lens by which to view the phenomenon under investigation.

### *Participants*

Prior to any participant recruitment and/or data collection, I completed all necessary procedures for obtaining approval from Iowa State University's Institutional Review Board (appendix B). Participants in this study include bereaved mothers who attend the *Mommies with Hope* support group. I used participant observation, interview, and focus group as my primary methods for data collection. I had a total of seven women who participated in the interview and/or focus group aspects of this study. Each of the seven women who chose to participate in this manner regularly attended *Mommies with Hope* and have each experienced some sort of perinatal loss, encompassing each of the following types: miscarriage, neonatal death due to a lethal prenatal diagnosis, neonatal death due to premature birth of twins, and stillbirth. Six of the seven women participated in this study through individual interviews and five of the seven participated in at least one of the two focus groups that were held. One of the women chose to participate solely in the focus groups. Further details pertaining to the procedures mentioned above will be outlined in more detail in the Procedures section of this chapter.

I gained access to this population through my role as co-founder/co-facilitator of *Mommies with Hope*. My partner in forming this group, also a bereaved mother, contributed to this study to some degree from the perspective of being a facilitator of the group, as well

as a bereaved mother receiving support through the group. In addition, she completed the required IRB training and was listed as a co-researcher on the project. Her role in the research primarily consisted of assisting with the facilitation of the focus groups, eliciting feedback from participants regarding their impressions of support through *Mommies with Hope*. Additionally, I was able to debrief with her after monthly “hope” meetings and also solicited her feedback as a peer reviewer for some of the conclusions I was drawing about how women were experiencing support through the group.

The specific criteria for interview and focus group participation in this study are as follows: Mothers who, 1) have experienced perinatal loss (miscarriage, stillbirth, neonatal death), 2) attend the *Mommies with Hope* support group, and 3) are at least 18 years of age or older. Originally, I anticipated that one participant would be the co-founder/facilitator of the group, who also meets all of the above-mentioned criteria. She did, in fact, participate, but not in the capacity at which I initially thought she would. Rather, her role consisted primarily of that as co-researcher, as described above.

Participants were encouraged to play an active role in the research, offering insight and feedback to inform the other co-facilitator and me about how they experience support through the *Mommies with Hope* support group. The degree to which participants chose to actively participate in this manner was entirely up to them, as they had the freedom to be as active or as inactive as they chose. To introduce the women who have chosen to participate in the interview and/or focus group procedures for data collection, I have written mini biographies for each of them, briefly describing the nature of their loss and their involvement in *Mommies with Hope*. I have also included details describing my relationship with each of these women.

*Sarah*

Sarah is a 27-year-old woman who has been attending Mommies with Hope since its inception in November 2007. It was in August of that year that Sarah had experienced the death of her 3-day-old son, Noah. Noah was diagnosed prenatally at 20 weeks gestation with a condition called anencephaly, the total absence of the brain and skull. Choosing to continue the pregnancy, realizing that the prognosis was 100% fatal, Sarah took part in a local Perinatal Hospice Program, which aimed to provide supportive, compassionate care as she and her husband anticipated Noah's birth and death. Sarah was able to carry Noah full-term and delivered him after being induced at 40 weeks gestation. After two days in the hospital, Noah was discharged to go home with his parents, where he visited his dog and spent some time outside. Sarah and her husband went with Noah to spend the remainder of his life at a local hospice facility, where they welcomed family and friends. Since Noah's death, Sarah and her husband have experienced two years of infertility, with the last year in which they have sought out the assistance of a fertility doctor. In January of 2010, they became pregnant again, without fertility treatment, only to find out that they were miscarrying a few days later.

I met Sarah over three years ago at church in the summer of 2006, just a couple of months after my daughter, Chloe's birth and death. We were newcomers to this church, so she did not know us during our pregnancy with Chloe. We became acquaintances who saw each other every Sunday, and initially, that was the extent of our relationship. When Sarah and her husband received the news of Noah's diagnosis, however, our Pastor connected us with one another and my husband and I were able to come alongside Sarah and her husband,

due to our similar experience with lethal prenatal diagnosis. We have grown to be close friends since that time.

*Elise*

Elise is a 30-year-old woman who has been an active participant in *Mommies with Hope* since our first meeting over two years ago. Elise found out about the group through Sarah, whom she had met at a hospital-based support group during the month prior to the start of *Mommies with Hope* in the fall of 2007. Elise also heard about the group through a local funeral home's grief symposium, an educational event geared toward connecting the bereaved with support in the community. Elise and her husband participated in the Perinatal Hospice Program after finding out midway through their pregnancy that their son, whom they named Dominic, had a combination of anomalies, primarily affecting his kidneys, that had a prognosis of death. Choosing to continue the pregnancy, they carried him to 32 weeks gestation, at which time Elise went into premature labor. Dominic lived for 45 minutes after birth. One year later, Elise became pregnant and within the same week in which she found out about the pregnancy, she began to miscarry. The loss occurred the week before one of our monthly "hope" meetings, which is when she shared about the loss with the group. Elise continues to come to *Mommies with Hope*, two-and-a-half years after the birth and death of Dominic, and appreciates the ongoing support provided by the group.

I met Elise for the first time when she attended our first *Mommies with Hope* meeting. Through her participation in the group, we have become friends and have occasionally done things as couples outside of the group, including invitations for her and her husband to visit our church and have lunch together. We regularly keep in contact via email as well.

*Ann*

Ann is a 34-year-old mother to four girls. In 2004, she experienced a miscarriage just toward the end of her first trimester of pregnancy with her third child. She has since given birth to two healthy children. Ann realized that she was experiencing a miscarriage when she and her husband went to the doctor for a routine prenatal visit. The nurse was unable to locate the baby's heartbeat with the doplar, which then led to the medical staff performing an ultrasound. The baby had no heartbeat, which is the moment that Ann realized her baby had died. She went through a D&C surgical procedure (dilatation and curettage) the next day, as recommended by her doctor and found great comfort in her husband's support and prayers during that time. Ann first attended Mommies with Hope in the Spring of 2009, nearly five years after her loss. She initially came to bring and support a friend who had experienced, in her words, a "greater loss" than her own. However, she found herself receiving comfort and encouragement from the women when she shared her own story of loss by miscarriage, and has continued to find validation through Mommies with Hope. Ann really enjoys being able to come alongside other hurting women who have been through something similar and sees the group as a way to "minister" to them.

Ann and I met for the first time in winter of 2008/2009. The church she was attending had approached the church I attend about combining. In this process, our churches began to coordinate events and activities together, which is how we met. Ann learned of *Mommies with Hope* through other women in the church and shared with me about the loss she had experienced in 2005. Since meeting just over a year ago, Ann and I have become good friends through church and through *Mommies with Hope*.

*Kate*

Kate is a 30-year-old mother of three living children, who experienced a second trimester miscarriage at 18 weeks gestation, and a first trimester miscarriage at 5-6 weeks gestation. Kate's first loss occurred quite unexpectedly in June of 2007, as she went to the doctor for a routine prenatal visit only to see that they were unable to find her baby's heartbeat. She went to the hospital that same day to be induced to deliver her son, Will. Kate initially came to the group in Spring of 2009. She came after being invited by her best friend, Ann, also a participant in this study. She has participated in several of the monthly "hope" meetings and one family social event. In summer of 2009, after having started to participate in *Mommies with Hope*, Kate became pregnant and began to miscarry shortly after finding out about her pregnancy. This first trimester miscarriage was like a "rollercoaster" for Kate, as the entire process was very long and spanned weeks before she received a clean bill of health.

I have come to be friends with Kate because shortly after her first time of coming to *Mommies with Hope*, she and her family began to attend the same church that I attend. She was invited through our mutual friend, Ann. Because of her active involvement in our church, I have come to know her through various women's ministry events and activities. Recently, Kate shared with me that she was expecting again. Given her history with pregnancy loss, Kate is nervous about the health of the baby she is currently carrying.

#### *Renee*

Renee is a 29-year-old woman who has been actively involved in *Mommies with Hope* since April of 2009. She came to the group after hearing about it from her sister-in-law, who in turn had discovered the group through a co-worker. Renee experienced the loss of twins, Owen and Ellie, after going into premature labor at 24 weeks along in her



pregnancy. Renee spent eight days on bed rest in the hospital to attempt to prolong the pregnancy as long as possible, giving her children a better chance of survival. Owen and Ellie were born into this world too soon and their little bodies could not take it. Owen died in utero, resulting in stillbirth. Ellie was born alive and lived for five hours.

I did not know Renee prior to her involvement in *Mommies with Hope*. Since she has been coming to the group, we have met outside of the group on occasion. She lives near Jennifer, the co-founder/facilitator of the group, and I know they have connected outside of the group as well.

#### *Hannah*

Hannah is a 30-year-old adoptive mother of one. Her journey to adoption started with her struggles with infertility and pregnancy loss. After seeking out the assistance of a fertility doctor, Hannah became pregnant with her first child, Benjamin. At nearly 19 weeks along in the pregnancy, Hannah began to “spot” and sought medical assistance. She was instructed to go home and come back for an ultrasound in two days, which she did. At the ultrasound, they discovered that she was dilated and was subsequently sent to the hospital where she was put on bed rest for two days. The amniotic sac was protruding due to the dilation and, unfortunately, there was nothing the doctors could do. She gave birth to Benjamin at that time.

Several months later, she and her husband decided that they were ready to try again became pregnant through fertility treatment. At 10 weeks into the pregnancy, Hannah found out that she was having twins. Then, about four weeks later, she began to spot and went to the hospital. Again, she was dilated and the medical staff could not stop the progression of the miscarriage and she delivered the twin boys at 14 weeks gestation. Ultimately, Hannah

was deemed to have incompetent cervix, which basically meant that her cervical muscle did not have the strength to remain closed during pregnancy.

After the pain of these losses, Hannah and her husband decided to pursue domestic adoption. It took several months of preparing the necessary paperwork and steps toward adoption. They waited for a year before receiving word that they had been selected as the adoptive parents of a baby girl who was due to be born three months after they received notice of their selection. Their daughter was born in the fall of 2009 and was able to come home from the hospital with Hannah and her husband, just two days after her birth.

Hannah has participated in *Mommies with Hope* since our very first meeting in November of 2007 and has come consistently ever since. She also attends my church, along with some of the other women who participate in *Mommies with Hope* so I have had the opportunity to connect with Hannah through church functions as well. We have become good friends over the past couple years, both through *Mommies with Hope* and church. Hannah does not intend to try for biological children in the future, but is excited about the opportunity to adopt again.

#### *Tia*

Tia is a 27-year-old woman who started attending *Mommies with Hope* in the fall of 2009. Tia is married with no living children. In June of 2008, Tia went into premature labor at 20 weeks gestation with her twins, Ryan and Grace. Each of the babies lived for approximately 45 minutes. Tia was eager to start trying to become pregnant soon after the loss of Ryan and Grace. In the fall of that same year, she learned that she was expecting yet again. However, in December, at 8 weeks along in the pregnancy, Tia miscarried. Since that

time, Tia has had difficulty becoming pregnant and has recently sought out assistance from a fertility doctor to become pregnant.

Tia first came to *Mommies with Hope* after learning about the group through a pastor at a local hospice facility where she volunteers. Tia was intrigued by the fact that *Mommies with Hope* was a “biblically-based” group as other formal supports she had received did not incorporate aspects of spirituality, which she states are important to her. I have come to know Tia primarily through *Mommies with Hope*, but do email back and forth with her from time to time to maintain communication between meetings.

#### *Description of the Mommies with Hope Support Group*

*“Everybody is understanding, caring, compassionate. They’re there to support and love, not to judge or make comments and sometimes nobody says anything at all and that’s the perfect thing to do. We can be open and honest and sometimes your feelings aren’t like what people would expect...and this group, that’s just how it is, that’s how you feel, and that’s fine.” (Sarah, Mommy to Noah and Baby S.)*

*Mommies with Hope* is a biblically-based Evangelical Christian support group that strives to live out the following mission: “Called to reach grieving women for Christ, providing comfort and encouragement rooted in Scripture.” *Mommies with Hope* was born out of Jen sharing the following scripture verses with me when we initially met:

“Praise be to God and the Father of our Lord Jesus Christ, the Father of compassion and the God of all comfort, who comforts us in all our troubles, so that we can comfort those in any trouble with the comfort we ourselves have received from God.”

(2 Corinthians 1:3-4, Holy Bible, New International Version).

We aim to fulfill this mission by offering monthly “hope” meetings and occasional social events. Established in November of 2007, we have been holding monthly “hope” meetings on the third Thursday of each month, which typically last from 7:00 – 9:00 p.m. The

locations of the meetings vary, ranging from a private room at a coffee shop, to the meeting room at a local church-owned building or community building. Most recently, meetings have been held at a local church. Privacy is ensured no matter which venue is utilized. In addition, a second group has been established in a nearby community, which began meeting in January of 2010. Training for the two facilitators of this second group was required. These facilitators had to attend the original *Mommies with Hope* group one to two times and also met individually with me to discuss the details of facilitating the monthly “hope” meetings. Furthermore, I have attended two of their three meetings to date and have been invited to offer constructive feedback based on my experience with the original group. Although each monthly “hope” meeting is different, there is a typical format for how the meetings transpire for each group.

The meetings are casual and usually begin with some sort of refreshment. Most women who regularly attend bring their personal bibles. For those who do not bring bibles, we have extras if they would like to follow along with any scriptures that are shared, though this is not a requirement. Once the women have had a chance to get their refreshments, we convene to start the support group meeting by beginning with a prayer, typically led by one of the facilitators.

If we have a new “mommy” in attendance, we start the meeting by each sharing our story of the loss of our child(ren) and also give the new woman the opportunity to share her story. For the past six to nine months, we have typically welcomed at least one new woman to the group each month and average anywhere from six to ten women in attendance each month. The act of sharing our stories allows for any similarities amongst losses to be established and for the new “mommy” to make connections with any of the other women

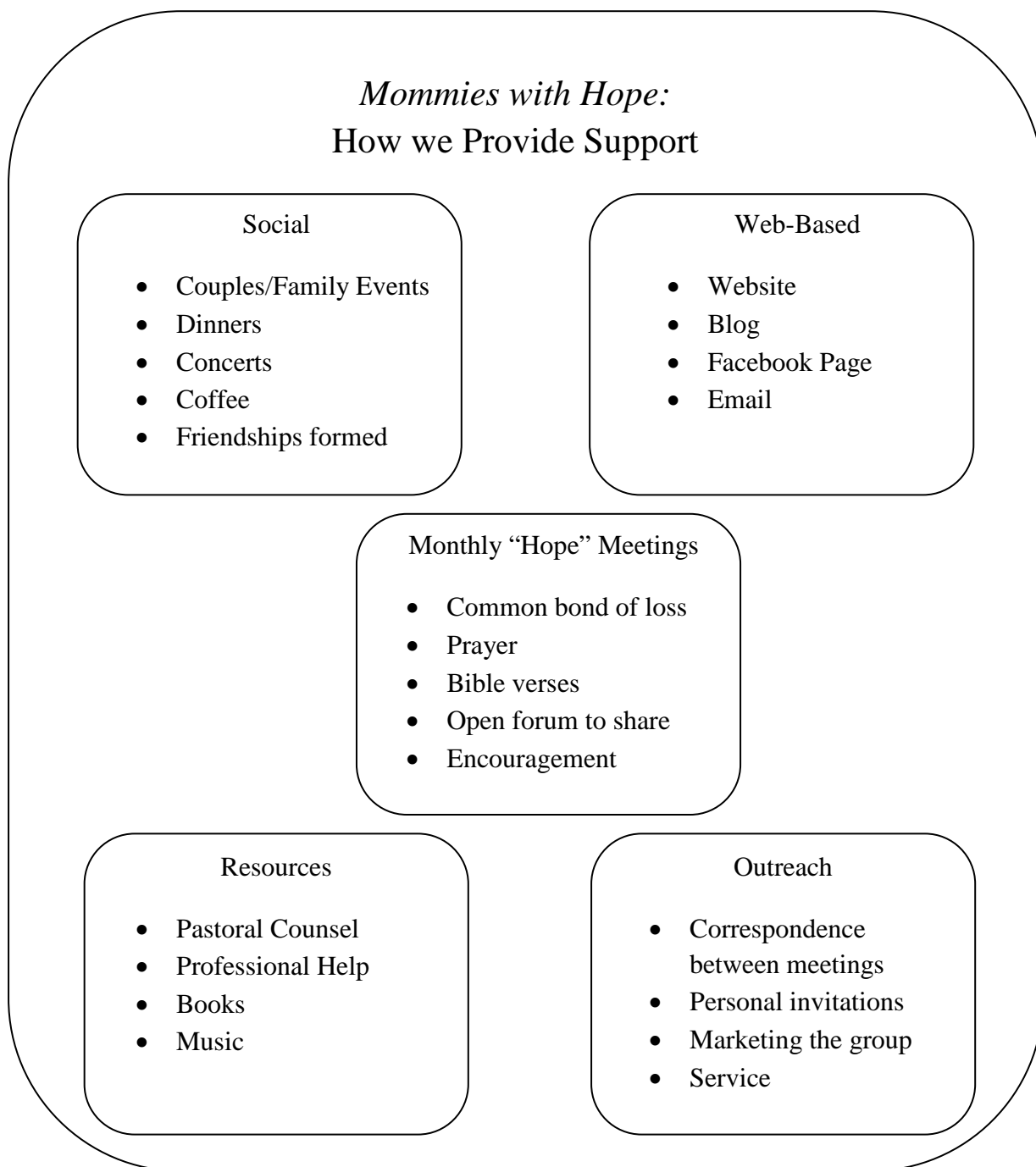
who regularly attend the group. If at our meeting everyone is familiar with each other's loss(es), we open it up for discussion and sharing right after the opening prayer.

The majority of our time together is spent in discussing specific issues, concerns, or struggles that the women are dealing with regarding the loss of their child. As facilitators of the group, Jen and I deliberately try to share bible verses from scripture that address the specific topics and concerns that emerge. Sometimes we come prepared with specific passages of scripture or stories/excerpts from a devotional or book as a basis for discussion and sharing. In either scenario, the format typically consists of free-flowing conversation and women are continuously encouraged to participate and share their personal thoughts. We aim to provide support based on scripture and are conscientious to address issues through this worldview. It is always our goal to view emotions, issues, and concerns through a biblical lens, keeping in line with our support group's mission statement, mentioned above.

Finally, we close each meeting with prayer. Typically, a facilitator will conclude in prayer and include any of the requests that were shared by each of the women in attendance. However, there are times when we give the opportunity for each of the women to pray out loud as a group, taking turns as they feel comfortable doing so.

In addition to the monthly "hope" meetings, we also meet for occasional social events, which have included any of the following: attending speaker events, scrapbooking, dinner, coffee, concerts, or doing service projects together. Several of these events in the past have included spouses or significant others. The social events serve as an opportunity for the women and/or couples to get to know each other beyond their losses. Other ways in which we provide support include through our web-based resources, which consists of a website, blog, and Facebook page. Each of these web-based supports has unique components

that allow for varied interaction and provision of support, including discussion boards, links to supportive websites, music, listings of books and scripture references to provide support, and information about upcoming events and/or meetings. In the visual below (Figure 1) you can see a snapshot of the way in which we aim to provide support through *Mommies with Hope*.

Figure 1. How we Provide Support through *Mommies with Hope*

### *Procedure*

Procedures for data collection included a variety of methods, including participant observation of the *Mommies with Hope* group, face-to-face, semi-structured interviews, and two focus groups. Prior to any interviews or focus group participation, I obtained signed informed consent from all participants (appendix C), detailing the potential benefits and risks of participating in this study, issues of confidentiality, and the overall purpose of this research. Also regarding consent, I requested a waiver for elements of consent from Iowa State University's Institutional Review Board for the participant observation data that I planned to collect throughout this study. The waiver was approved, which meant that I was not required to obtain informed consent for the women who came to our monthly meetings and/or social events that were held in conjunction with *Mommies with Hope*. The rationale for requesting a waiver of consent for this observational data is that I did not want to jeopardize these women's participation experiences in the support group. I argued that it was more of a risk that they not return for additional support if they felt their participation in the group involved being a part of a research study, despite its voluntary nature. Further, the women who attended the monthly meetings and/or social events were not asked to do anything beyond what they would have already done in their typical schedule, and therefore, they were not asked or required to participate in any additional procedures for data collection. I simply observed them in their natural setting. All interview and focus group protocols/questions and data-collection instruments, as well as the informed consent document, were approved and stamped by the Institutional Review Board prior to any data collection procedures. Participant observations of mothers as mentioned above, occurred on a consistent basis throughout the course of data collection through prolonged engagement



with the mothers through participation in the *Mommies with Hope* support group. The support group meets on a monthly basis, as well as at additional times for social events or outings. I collected a total of 17 observations, which included 10 monthly “hope” meetings, five social events, and two unique interactions (special prayer meeting and a women’s conference).

For all data collection opportunities, I completed an Observation/Interview Summary Sheet (appendix D) during the observation/interview or immediately following the encounter. This form served as a portion of my field notes. Additionally, I wrote in a methodological log where I took notes and wrote down questions about the methodology, kept field notes, and also did some personal journaling throughout the research process.

I conducted individual interviews with seven mothers in the group. Mothers were chosen for interviews based upon initial participant observation data. More specifically, I chose mothers based on several factors, including: length of attendance in the group, perceived emotional stability, and perceived comfort level with the research process. Interviews typically lasted between 45 and 75 minutes in duration and were recorded with a digital audio recorder, and transcribed verbatim. Transcriptions were coded and analyzed throughout the course of this study, simultaneous to ongoing data collection. Interview questions focused on how the individual mothers experience support in the *Mommies with Hope* support group. Examples of specific interview questions include: What has the grief process been like for you? Can you think of times when you have felt unsupported in your loss? How would you describe Mommies with Hope to others? How has your participation in Mommies with Hope validated your experience with loss? Please see the interview protocol for a complete listing of questions (appendix E). Over time, interview questions

began to include elements of a perception of the group as a “safe place.” Examples of such questions include: What does the concept of a “safe place” mean to you? Are there places you feel it is “unsafe” to discuss your loss experience? The emergence and evolution of these questions occurred as a result of simultaneous data collection and analysis, which is characteristic of qualitative research in general. A focus on individual experiences was achieved by using reflexive dyadic interviewing (Ellis & Berger, 2002) with mothers about experiences with perinatal loss and their support experiences based on participation in *Mommies with Hope*. Reflexive dyadic interviewing flows as a conversation and allows for the researcher to disclose personal information and experiences related to the topic under investigation (Ellis & Berger, 2002). This type of interviewing was necessary, given the sensitive nature of the issues that were discussed between the interviewer and the participants, as well as adhering to a collaborative approach called for when conducting a critical ethnography.

Finally, I conducted two focus groups with the mothers. The aim of the focus groups were to facilitate a dialogue among participants about how they experience support and validation for their loss(es) through the *Mommies with Hope* support group on an ongoing basis as well as how they would like to be supported. Such a discussion was geared toward shedding light on how we [facilitators] can address the support needs of the women, and the group as a whole, in current and future provision of support. Additionally, the focus group helped determine specific supportive and/or non-supportive actions that served not only to inform how we provide support through *Mommies with Hope*, but also provided insight into how other groups ought or ought not to offer support. Equally important and in the spirit of reciprocity, the focus group provided the women with a sense of ownership of the group,

giving them a voice in matters pertaining to the delivery of support through the group, and allowing them to collaboratively and actively engage in the formulation of ideas that will enhance the group as a whole. I initially set out to conduct one focus group, but made the methodological decision to attempt a second “mini focus group.” The reason for this decision was made, in part, due to the fact that the digital voice file of the focus group was deleted due to a glitch in the recording device before I had the opportunity to transcribe the data. In addition, the turnout for the focus group was lacking and it was conducted after a special prayer meeting that we held for a woman in the group, which I feel impacted attendance and discussion. Thus, a second focus group was held, in conjunction with the solicitation of feedback via email (appendix F).

For a complete listing of the questions that were posed during the focus group, please see the attached protocol (appendix G). The first focus group lasted approximately 75 minutes and followed a special prayer meeting that we held for a woman in our group who had experienced a recent miscarriage. As previously mentioned, I chose to hold a second “mini focus group” at another time, which lasted for approximately 30 minutes and was scheduled to occur just before one of our monthly “hope” meetings. Each focus group was audio-recorded, but the second one was the only one that was transcribed, due to the technological glitch that caused me to lose the first focus group, as described above.

By way of incorporating peer review, which is discussed later in this chapter, Jen (co-facilitator of the group) and I debriefed after the monthly meetings and focus groups. Our debriefing meetings consisted of a discussion of our observations, impressions, and ideas related to the meetings and the focus groups that took place. I wrote about these debriefing meetings in my methodological log.

### *Analysis*

I conducted an ethnographic analysis of the data through the use of participant observation data of the *Mommies with Hope* the group as a whole, as well as through individual interviews and focus groups, which occurred with select women who participate in the *Mommies with Hope* support group, as described in the participants section above. I invited women to participate in this study based on their consistent attendance and participation in the group as well as my perception of their emotional readiness. The critical element of this study is embedded in my view of perinatal loss as a disenfranchised grief, as emphasized and supported through the literature in Chapter 2 of this study. I conducted simultaneous data collection and analysis throughout the course of this study. According to O'Reilly (2005), "analysis and data collection are interlinked" in ethnographic research (p. 181). Thus, it was necessary to actively engage with analyzing the data as I went, re-examining my initial assumptions and beliefs about the data and reflexively write throughout this linked process.

Despite the cyclical nature of this analytic process, I followed a standard protocol in place for data analysis. As a reminder, I collected interview, observation, and focus group data. I recorded the interviews and focus group with the use of a digital voice recorder to later be transcribed. Additionally, I kept a notebook comprised of field notes, methodological log entries, and completed observation/interview summary sheets. I was prepared for the possibility of having additional sources of data, including artifacts presented by the mothers themselves, such as photos, scrapbooks, journals, letters, and devotions. Such artifacts that were included in this study were emails and comments posted on the *Mommies with Hope* blog, which were subsequently used as data in the current study. With regard to

analysis of such artifacts, those items were recognized as visual data (O'Reilly, 2005) and treated as such. According to Robinson (2003), "By looking at the social processes that center on a material object, we may uncover the social processes of the everyday world through which members make meanings." (p. 4). O'Reilly (2005) asserts that some ethnographers see the use of the visual as "more emancipatory and powerful than the use of text" (p. 168).

Pertaining to the interview, observation, and focus-group data, I followed the procedures of taking field notes and completing observation/interview summary sheets as previously mentioned. I audio-recorded each interview with a digital voice recorder and transcribed each individual interview verbatim. The digital recorder I used connects directly to a computer, which enabled me to securely store audio files, as well as any transcribed text documents. The electronic files were password protected to ensure confidentiality and the use of pseudonyms in any written transcripts was employed. With regard to the use of pseudonyms, it is important to note that all women who participated in this study were assigned pseudonyms. However, I used the actual names of all children in this study. Before doing so, I asked the women what their preference was and each woman wanted me to use the actual names of their child(ren) and saw it as a way to honor their babies who died.

The second focus group was transcribed and stored the same manner as the interviews, as described above. The first focus group I conducted, however, was not transcribed before a glitch in the recording device inadvertently deleted the voice file. When I attempted to retrieve the recording in the password-protected computer file where I had stored it, the auto-save function on the recorder deleted the file from the computer, making it

impossible for me to transcribe the initial focus group. Thus was the reason for conducting a second focus group.

Having transcriptions of the interviews and focus group, combined with all field notes based on participant observation data, I had the ability to conduct an ethnographic analysis of this written data by coding and logging the data generated through these above-mentioned means. Madison (2005) suggests asking the following question of oneself when beginning to code and log data: “What is the best way to group or cluster all this material so that it will help me focus more clearly on my analysis or how I wish to present this material?” (p. 37). Keeping this question in mind, focusing on my overall purpose and research questions, I coded the transcriptions of each interview by using the following general process: 1) writing synthesis statements and notes in the margins, 2) using synthesis statements and notes to group similar topics and develop common clusters, 3) writing the cluster/theme name in front of excerpts of the narratives. I have included examples of this in the appendices (appendix H). More specifically, I read through the transcripts, field notes, and interview/observation summary sheets several times, writing notes in the margins and forming synthesis statements pertaining to specific portions of data. From there, I examined the synthesis statements to form broader clusters or themes, naming them with one word or a short phrase, narrowing down the larger clusters into themes. I examined the related topics within each cluster throughout the process of analysis, comparing and contrasting the topics to determine whether they belonged together or in a different cluster. Some topics were eliminated altogether or were deemed sub-themes. I coded sub-themes in the same manner. To easily access the coded categories and themes, I used a color-coded system, highlighting portions of narrative within the data. The color that I highlighted portions of data with corresponded to

the themes and/or sub-themes that had previously been identified through the analysis process described above. Please see the example provided (appendix H), which includes the final list of color-coded themes and sub-themes. I have included a number of examples in this appendix (appendix I), which includes a sampling of interview/observation notes and summaries, coded transcripts, member-check documents, and a progression of concept maps.

### *Addressing Issues of Trustworthiness and Rigor*

Davies and Dodd (2002) explored the issue of rigor in research, particularly qualitative research. They suggest rigor can be addressed in qualitative research by incorporating the following measures: “attentiveness, empathy, carefulness, sensitivity, respect, honesty, reflection, conscientiousness, engagement, awareness, openness, context” (Davies & Dodd, 2002, p. 288). They argue that these terms mentioned above are just some of the ways in which we can begin to conceptualize the concept of rigor in qualitative research. They also assert that the notion of rigor takes on a different meaning for qualitative research than it does in quantitative, considering the varying purpose and goals of these distinctly different approaches to research (Davies & Dodd, 2002). With these ideas from the onset of this study in mind, I was conscientious of the need for attentiveness to the research process for this study, making an effort to be completely transparent and making visible the way in which I collected and analyzed data.

Specific actions I took to address the pertinent issues of trustworthiness and rigor, included conducting member-checks, triangulating the data, making use of a peer-reviewer, and by being completely reflexive and transparent throughout the simultaneous data collection and analysis process. Member-checks consisted of providing participants with my write up of their specific “bio”, as included above, as well as select interpretation of themes

and findings, based on participant narratives. Participant feedback helped inform any adjustments that I made to the developing themes. In qualitative research, triangulation is a technique to ensure rigor of the research. Patton (1999) identifies four types of triangulation, three of which were employed to some degree in the current study: 1) methods triangulation, 2) data triangulation, and 3) analyst triangulation (Patton, 1999). I made use of various types of data for analysis in the current study, which I collected through various methods, including participant observation data, interviews, and two focus groups. In addition, some email and blog post comments provided by women were utilized and aided in triangulation of the data. Additionally, triangulation of the data occurred through my personal experience with the phenomenon of perinatal loss and my role as co-founder/facilitator of the *Mommies with Hope* support group, the reported support experiences of the mothers who participated in the study, and the perception of the other co-founder/facilitator of this group who is also a bereaved mother and who aided in the research as a peer de-briefer and co-researcher in this study. Also by way of peer review, I elicited the assistance of a colleague who examined the visual framework I had developed based on the findings from this data. The reviewer is a 39-year-old Assistant Professor at a nearby college, trained in qualitative research. She offered insight that contributed to the format of the visual representation of my findings.

To further ensure rigor, my continuous reflexive writing in a methodological log, served as a record of my own personal biases and interpretations of the findings throughout the data collection and analysis procedures, and was used as a form of data in the analysis of this study. Carspecken (1996) cautions that critical researchers must be careful that values do not dictate findings. Rather, we ought to examine our values in how they guide our research choices, including what we will study, our decisions throughout the research



process, and how we will use the findings from our research (Carspecken, 1996). Thus, I have made every effort to transparently examine the data from my personal perspective as a bereaved mother, Evangelical Christian, and co-founder/facilitator of the group.

Additionally, I consider the perspectives of other mothers who chose to participate in this study, and of the other co-founder/facilitator of the *Mommies with Hope* support group, Jen, whom is also a bereaved mother. I acknowledge the impact that my personal values have on my approach to the study and the research decisions that I made throughout the research process. The women's experiences, regardless of whether they lined up with any preconceived notions I may have had about how women experience support through *Mommies with Hope*, are of prime importance in this study.

### *Ethical Considerations*

I acknowledge that I hold multiple roles in relation to the current study, including my role as researcher, my role as co-founder/facilitator of the *Mommies with Hope* support group, and my role as a bereaved mother. Each of these roles influences my approach to the research. As a researcher, I aim to address my specific research questions posed above, geared toward women's support experiences through *Mommies with Hope*. As cofounder and facilitator of the support group, I want to know how to improve upon the provision of support for the women who attend the group. Finally, as a bereaved mother, I have a passion for and understanding of the issues faced by women who have experienced perinatal loss. Regarding the issue of ethics in critical ethnography, Madison (2005) asserts,

“An ethics of critical ethnography does not use human beings as a means to an end.

We do not gain rapport and trust to simply get the data and then run in order to

accomplish our own goals while leaving subjects vulnerable or feeling exploited. An

ethics of ethnography considers the direct well being of the Other as the first priority”  
(p. 85)

As previously mentioned, *Mommies with Hope* was established in November of 2007 and “mommies” have been meeting on at least a monthly basis since that time. Given this, there is a core group of women who dedicatedly come to the meetings and events. Through our shared experience of loss and the intimate sharing that has occurred amongst us, we have become a close-knit group of friends. I am cognizant that this too was an ethical concern to be aware of in the context of this study. Still, confidentiality was ensured throughout the research process, just as it is maintained in the support group setting.

Also an important issue to consider in the context of ethics is the issue of reciprocity between myself as researcher, and the women who so willingly gave of their time to participate in this study. As discussed further in the implications section of this study in Chapter 5, a goal of the research is to provide information that will serve to enhance the way in which support is provided through *Mommies with Hope*, not only for this specific group of women but potentially for additional groups that are started in other communities in the future. Thus, the women who participated in the study have been given the opportunity to directly contribute to the improvements made to the group itself, some of which have already been implemented.

## CHAPTER 4. FINDINGS AND DISCUSSION

### *Distinguishing Support Provision from Support Experience*

This chapter focuses on the findings of the qualitative data that I have collected over the past year, interpreted through a critical lens, viewing perinatal loss and bereavement as a disenfranchised grief. As previously stated, the questions of this research are: 1) How do mothers experience support through participation in the *Mommies with Hope* support group, 2) How does the group help or hinder bereaved mothers' support experiences, and 3) How does participation in the group validate mothers' experiences with perinatal loss?

The encompassing themes and sub-themes described in this chapter will address each of these research questions above. These findings are a result of collecting the following forms of data, as described previously: 1) participant observation, 2) individual interviews, and 3) two focus groups. Additional artifacts that surfaced throughout the data collection and analysis procedures included emails and blog posts and comments pertaining to the research study, which were also analyzed and contributed to the following findings which will be reported in this chapter. Finally my personal field notes which include interview/observation summary sheets and my methodological log is also considered in the findings of this study.

The findings are organized in Figure 2, which provides a visual framework for the following: 1) Lack of support: Messages Conveyed by Others, 2) How we (*Mommies with Hope*) Provide Support, and 3) How *Mommies* experience support. The perceived lack of support reported by mothers, part one of the visual framework, is discussed throughout the findings of this study and supported through the current literature. Part two of the visual framework, How we Provide Support, details the provision of support through *Mommies with Hope*. This was explained in great detail in Chapter 3 of this study. Part three of the visual

framework, How *Mommies* experience support, is the focus of Chapter 4. These findings address the initial questions of this research and will be presented in light of the purpose of this study: to explore the support experiences of mothers who participate in the *Mommies with Hope* support group.

It is important to distinguish the difference between how support is provided and how support is experienced. Understanding how support is provided by the group is an important prerequisite for understanding how women experience support, the aim of this study. Such understanding offers insight for how to best support women who choose to participate in the group to current and future group facilitators. This chapter aims to focus primarily on women's support group experiences, including aspects that help and/or hinder their support experiences, as well as describing how women experience validation for their perinatal loss experiences. I have provided a table (Table 1) below to aid in comprehending how the specific encompassing themes and sub-themes address the research questions posed above. Finally, these findings are represented visually and textually in the pages to follow, acknowledging their perinatal loss experiences as a form of disenfranchised grief.

Table 1. Visualizing Research Questions and Corresponding Themes

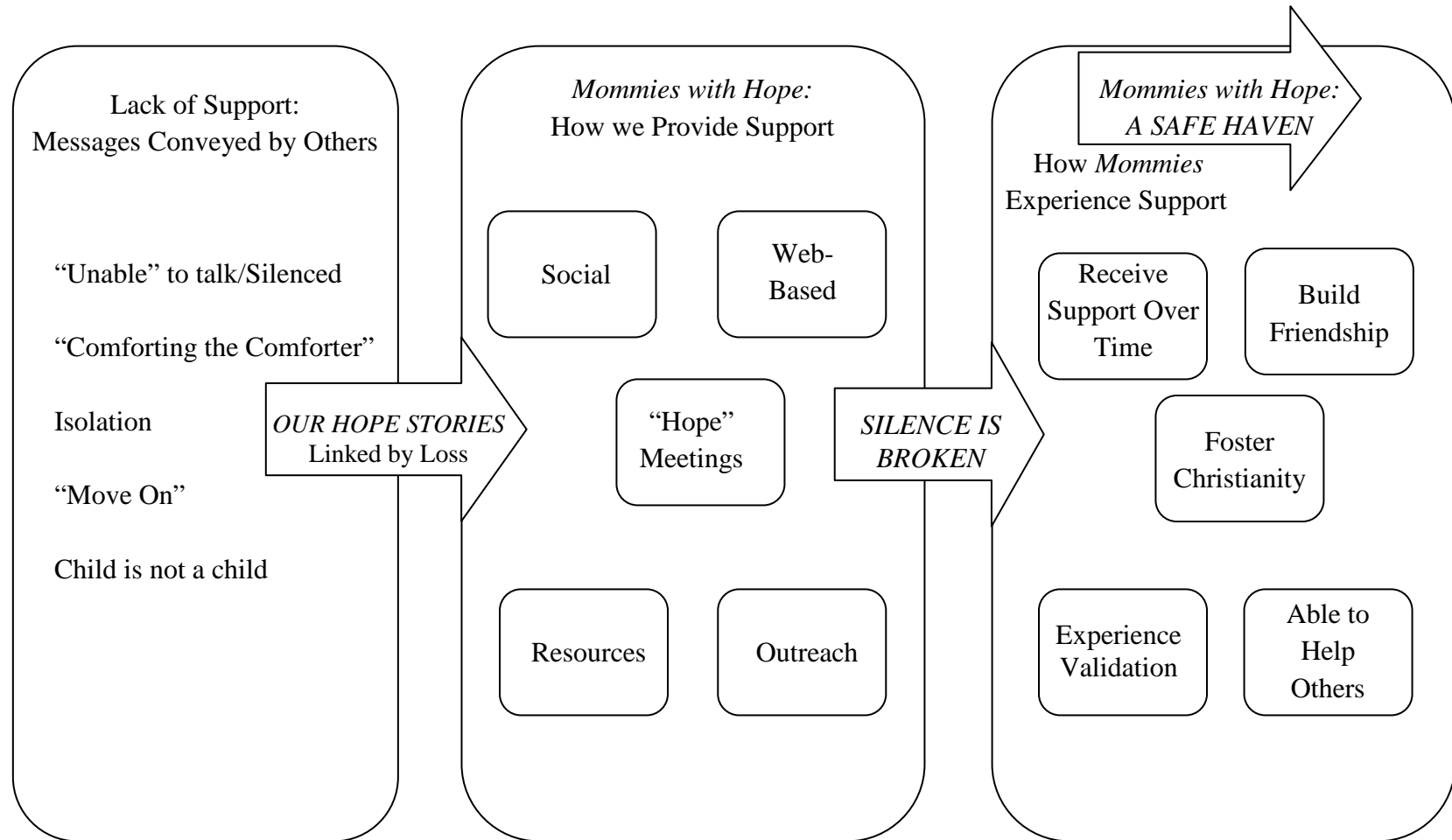
	Q. 1 <sup>a</sup>	Q. 2 <sup>b</sup>	Q. 3 <sup>c</sup>
Encompassing Theme(s)			
Our Hope Stories: Linked by Loss	X	X	X
Silence is Broken	X	X	X
Mommies with Hope: A Safe Haven	X	X	X
Sub-Theme(s)			
Receive Support over Time	X	X	
Experience Validation	X	X	X
Build Friendship	X	X	
Foster Christianity	X	X	X
Able to Help Others	X		

<sup>a</sup> How do mothers experience support through participation in the Mommies with Hope support group?

<sup>b</sup> How does the group help or hinder bereaved mothers' support experiences?

<sup>c</sup> How does participation in the group validate mothers' experiences with perinatal loss?

Figure 2. How Women Experience Support through *Mommies with Hope*



### *Encompassing Themes*

Throughout the process of data collection and analysis, the following three encompassing themes emerged: 1) Our Hope Stories: Linked by Loss, 2) Silence is Broken, and 3) Mommies with Hope: A Safe Haven. Each of these three encompassing themes is central to leading women to the group. Additionally, these encompassing themes create an environment such that *Mommies* are “able” to safely discuss their loss experiences, as conveyed by each of the women. These encompassing themes envelop the entire support experience of the women who attend the group due to the shared experience of loss, the ability to share openly within the group, and the perception of the group as a safe haven. Each of the above-mentioned encompassing themes illuminates the disenfranchisement felt by women in contexts outside of the group, as described in more detail below.

#### *Our Hope Stories: Linked by Loss*

Women who participated in this study are linked by their shared experience of perinatal loss. Having that common bond with one another allows women to more readily connect with one another in the group setting, as opposed to the reported feelings of isolation experienced in settings beyond *Mommies with Hope*. Although the losses of those whom I interviewed varied in type, ranging from early miscarriage, to premature birth of twins resulting in death, to stillbirth, to the neonatal death of a child three days after a full-term birth, each of the women acknowledged that they appreciate being “able” to relate to other women who have “been there.” It is such loss that qualifies each of these women to participate in the *Mommies with Hope* support group. We often talk in the group about how we are so thankful that we have each other for support, but sad to know what brought us together: the loss of our children. It is this shared experience of loss, coupled with a

perceived lack of support outside of the group, which unites us and allows us to give and receive support to and from one another. While women repeatedly cite family and friends as sources of support, they distinguish the women from *Mommies with Hope* as an invaluable source of support, given the fact that each woman there has experienced something similar to herself.

In an interview with Elise, she describes the significance of being linked by our losses when she expresses the following, "...there's just something about being able to talk to other people that have been through the exact same thing." Later in that same interview, she comes back to this notion and explains that the group offers a forum for women to share by stating, "...someone else knows what you're going through, what you have been through, and you know you can feel really alone when you go through something like this" (*Elise, Mommy to Dominic and Baby C.*)

Similarly, Hannah acknowledges this sentiment when she says,

"It helps knowing other people have gone through it, so you don't feel like you're the only one in the world...it feels good to talk about it with someone who knows, who's experienced it because a lot of people have no clue what it's like to lose a child... I come for the support and just knowing that there are other people out there that have gone through the same thing because that's comforting. You don't like to feel alone"

(*Hannah, Mommy to Benjamin and her Twin Boys*)

Both Hannah and Elise allude to the idea of feeling isolated in their loss experiences outside of *Mommies with Hope*. Kate makes a similar statement in recalling her loss experience that occurred three years ago, prior to participation in *Mommies with Hope*, by saying, "It was hard because I didn't know anyone who had been through a similar situation." For Sarah, the



fact that we are linked by our losses is one of the most helpful aspects of the support group experience. When asked about those things that are “most helpful” about *Mommies with Hope*, part of her response includes, “...just being able to share and being able to talk and having that common bond.” (*Sarah, Mommy to Noah and Baby S.*)

Along with the mere shared experience and being linked by our losses, women express a sense of being able to relate to one another’s feelings surrounding the loss experience. Elise expresses this notion when she says,

“...just knowing that I’m not alone in what I went through and just having everybody in the group as a sounding board to validate my feelings and know that, yeah, most of the feelings I’m having or have had, other people have had as well, and it’s just nice to be able to share that and to have that kind of common experience.”

(*Elise, Mommy to Dominic and Baby C.*)

Ann relates to this idea of shared feelings by saying, “I can relate to them [other women in the group] on a level of being a woman and understanding how it feels to hurt when you’re dealing with the loss of a baby.” (*Ann, Mommy to Baby H.*)

Tia talks about the significance of such shared experiences and also discusses the hope that she is given by seeing women who have gone through something similar in *Mommies with Hope* when she says,

“..the fact that other women have gone through this...I’m amazed that there’s two or three people in this group that have gone through almost the exact same scenario – twins, a boy and a girl, I mean the similarities are almost eerie, but I feel that helps me. And to see that they’re still walking, they’re still going, they’ve survived it. It

was hard and it still breaks their heart, but they got through it somehow. It gives me hope that I can do that too.” (*Tia, Mommy to Ryan and Grace*)

What a powerful statement Tia makes when she says, “It gives me hope that I can do that too.” She is finding in hope in seeing others who have gone through something similar and who have come out on the other side. She is becoming a *Mommy with Hope*.

### *Silence is Broken*

As previously mentioned in my researcher positionality statement in Chapter 3, the issue of silence permeates perinatal loss experiences, particularly in the case of miscarriage. I wrote candidly about my own struggle with such silence and chose “To Not be Silenced” after going through a first-trimester miscarriage, challenging other women to recognize their own losses as valid and significant and that they do not have to feel isolated in. Although I was admittedly torn about whether or not to tell about the miscarriage, the *Mommies with Hope* blog was a place where I knew I could openly share about that miscarriage experience and be understood and my decision to tell would be affirmed. I did not have to worry about whether I would hear an insensitive cliché or unwelcome dissent in response to my disclosure. I trusted *Mommies with Hope* to be a supportive environment and it was. Comments to the blog post that I wrote were supportive and reaffirming that I had made the right decision to tell my secret. As a facilitator of the group and a bereaved mother, experiencing yet another loss, I felt as though I was able to demonstrate to the women that we do not have to be silent in our loss experiences, even though I was beginning to understand firsthand what this silence was all about. Other women also had this experience of breaking the silence. One of the comments to this post relates by stating,

“Thank you for writing this. I also lost a child at six weeks and have felt at times that I don't have permission to grieve as others do. It's amazing how we can hold a little one in our bodies for awhile and our hearts for always.” (*Anonymous*)

In reading this anonymous writer's words of affirmation and understanding, I knew I had made the right choice – to not be silenced. There have been several occasions since I wrote that particular blog post, just over six months ago, where I or other women in the group have been able to pass it along to yet another woman who experienced a first trimester miscarriage and feels “silly” about coming to a support group or grieving her loss.

Elise relates to this idea of silence and first trimester miscarriage when she describes her decision to tell people about their loss at 8 weeks gestation. She says,

“...telling people of the miscarriage was one in the same with telling them that we were expecting, so that was just a really bittersweet kind of conversation...it happened so early on. It's easy to fall into that ‘oh I was only 5 weeks along’ mentality.” (*Elise, Mommy to Dominic and Baby C.*)

In this same discussion, Elise goes on to admit that she and her husband did not disclose the miscarriage to a couple whom they were very close friends with for nearly four months after the loss. When probed further about her reasoning for keeping silent about the miscarriage to this couple in particular, Elise responds, “...maybe I thought that they wouldn't understand and I wouldn't get that validation so I was scared to tell them.” (*Elise, Mommy to Dominic and Baby C.*) When talking with Kate about her recent miscarriage at six weeks gestation, she states, “Some people still don't know. Some people knew that I was pregnant and I haven't even told them that I miscarried.” (*Kate, Mommy to Will and Baby S.*) It is interesting to take a step back and examine the typical practice of pregnancy disclosure in our

culture. It is almost expected that women do not tell that they are expecting until they near the end of their first trimester of pregnancy around 12 weeks gestation. In fact, I can personally call to mind a number of occasions where women have disclosed pregnancy early on, at six or seven weeks gestation for example, only then to hear others scoff at the audacity these women had to tell anyone they are pregnant so early on. I state these examples purely to point out that women are silenced about pregnancy, in general, from the beginning. Thus becomes the case of pregnancy disclosure and miscarriage often becoming “one in the same,” as mentioned by Elise. It is clear to see why so many women experience miscarriage in silence, even though they are not alone.

Another aspect to this silence experienced by women may include fear of what others will say or how they will react, or the reality that the woman may very well be the one who ends up providing comfort to the person they just told, which will be discussed in greater detail below.

When we are talking about the issue of silence and being able to talk about our children whom we have lost to miscarriage, Ann asserts a similar idea in saying,

“I think you keep your emotions and your feelings bottled up. They’re tucked inside of you so much because of the response that nine times out of ten you more than likely receive from people when you share with them, you know.” (*Ann, Mommy to Baby H.*)

She goes on to say that she typically restricts conversations about her loss experience to those ladies who are a part of the *Mommies with Hope* group. Her ability to express her thoughts and feelings about her loss to these women is a direct result of the silence being broken. Ann explains,

“I feel like it’s [talking about the loss] more exclusive to being in the Mommies with Hope meetings and talking to those women about it. I honestly, to tell you the truth, I don’t...I mean there are very few times or opportunities where I would feel comfortable elsewhere to share that [her loss experience] with a group of people.”

*(Ann, Mommy to Baby H.)*

In discussing the issue of silence with women throughout the interviews, as well as hearing them talk about this issue in the group setting, it became more and more apparent, as previously mentioned, that women tend to remain silent about their loss experiences because they often cite that they are the ones who end up “comforting the comforter.” In fact, every woman I interviewed used these exact words of “comforting the comforter.” In other words, the women who have experienced loss should be the ones receiving the comfort when the loss of their child becomes the focus of a particular conversation. Reversely, however, women report feeling as though they become the ones who provide comfort to the other person, consoling them for asking a seemingly innocent question such as, “Do you have any children?” It is a question that most people would not think twice about, but for a woman who has experienced loss, it may be the ever-dreaded question that sets into motion a whirlwind of thoughts and emotions as she formulates an appropriate response. The women who participated in this study talked about the various thoughts that run through their minds when such a question arises. They question themselves, asking things like “Should I say anything about our baby who died? Will they think I’m weird for saying anything about him/her? Will I ever see this person again? What’s the point?” Women reported that it depends on the person and situation as to whether or not they choose to disclose information

about their child who died in such situations, again another way in which women are silenced, as discussed above.

In talking about this issue of silence, Hannah refers to her experience of keeping quiet about the loss of her twin boys, after having already experienced second trimester of her son, Benjamin, when she says, “I don’t want to burden anybody, because I don’t know if I want to tell the whole story again.” (*Hannah, Mommy to Benjamin and Twin Boys*). When women do choose to tell about their child who died, the reaction from the inquirer tends to reverse the roles of the two parties, with the bereaved mother becoming the comforter as opposed to the one receiving the comfort, thus “comforting the comforter” as the women who participated in this study described. Sarah expresses, “I’m going to tell them to more than likely have the tables turned again to where I’m making them feel better about what I went through, because that’s what happens a lot in these situations.” (*Sarah, Mommy to Noah and Baby S.*) Here, Sarah is explaining her expectation that she will, in fact, be “comforting the comforter.”

When talking with Elise, I ask her about the typical reaction of people when she chooses to disclose her losses to individuals. She reported that people react by saying, “Oh, I’m sorry! [gasping]” She then says, “It’s like they’re immediately just shocked and want to change the subject right away...the person who should be getting the comfort ends up being the comforter and saying, ‘Oh no no, it’s okay, it’s okay.’” (*Elise, Mommy to Dominic and Baby C.*) Elise goes on to tell about a picture of Dominic that she keeps on her desk at work, right next to a picture of her living child who was born two years after Dominic’s birth and death. People comment on her daughter’s picture, but neglect to ask about or comment on her picture of Dominic. In telling about this story, Elise asserts,

“...maybe they’re shocked that I have his picture on my desk, but I don’t know. I don’t know if it’s the fact that the picture of him was after he passed and I guess you can probably tell that in the picture, so I don’t know if that kind of puts people on edge or uneasy or whatever. But to me, he’s my son and he’s beautiful.” (*Elise, Mommy to Dominic and Baby C.*)

Her telling of this story, in particular, was so touching to me. I too have a picture of Chloe on my desk and no one dares ask about her. Her little hat is covering the entire top half of her face, due to the abnormalities, and still no one asks. Elise says it all when she so powerfully states, “But to me, he’s my son and he’s beautiful.” (*Elise, Mommy to Dominic and Baby C.*) Others do not recognize the beauty in a picture of a tiny baby, born too soon, that has been taken after that baby died. The coloring may be “off” or something may not look just quite right. To others, it may seem morbid to have a picture of your dead baby on your desk at work. To the mother of that baby, however, that picture may be all she has.

Similarly, Sarah describes a situation at her work where she too has found herself comforting others rather than receiving comfort herself when opportunities to talk about Noah have surfaced. She goes on to describe other situations in which she feels silenced and says, “I can’t just bring it [the loss] up or bring Noah up wherever, I mean not everyone gets that. I think it even weirds some people out.” (*Sarah, Mommy to Noah and Baby S.*) Elise shares a related thought when she says,

“...it just kind of makes it hard when no one else brings him up, it’s not like I want to just throw it out there. I don’t really know how to wedge it into the conversation. So that makes it hard.” (*Elise, Mommy to Dominic and Baby C.*)

The women find themselves in a difficult situation with whether or not to share about their loss experience, evidenced by the various quotes and stories shared above. They have a propensity to be silenced in miscarriage due to the social expectation to wait before disclosing pregnancy. Then, even in later term miscarriages or losses resulting from stillbirth or neonatal death, women avoid talking about their children because they anticipate having to “comfort the comforter.” This silence contributes to the perpetuation of perinatal loss as a disenfranchised grief where women do not receive the acknowledgment, support, and/or validation that their loss experience warrants.

*Mommies with Hope: A Safe Haven*

Repeatedly, the women I interviewed and observed indicated that *Mommies with Hope* was a “safe place.” They felt “able” and “comfortable” talking about their loss experiences and their feelings related to their losses. Women perceived *Mommies with Hope* as a “Safe Haven”, which in turn made it possible for the women to experience support in various other ways, which will be described in more detail in the sub-themes section of this chapter below. To elaborate upon this idea of *Mommies with Hope* as a “Safe Haven”, consider the words of Ann as she discusses her rationale for continued participation in *Mommies with Hope*:

“...it has been an encouragement to me and it has been a place that I know that my feelings are valued and my expression is valued and that I can talk about that baby openly and not feel like I’m getting a roll of the eyes or ‘Why is she still hung up on that?’”(Ann, *Mommy to Baby H.*)

Based on Ann’s words above, it is apparent that there are situations where she does not feel comfortable and/or like her “feelings” and “expression” pertaining to her loss is valued. In



an interview with Sarah, the following dialogue, related to Ann's words above, took place as we discussed this idea of *Mommies with Hope* as a "safe place":

Me: "So if we say that the group is a safe place, that then assumes that there are settings outside of the group that are not safe."

Sarah: "Oh yeah, there are settings outside for the group where you have to guard what you say. You share too much and you feel like people are looking at you like you're a bad mother, or people are looking at you like you're a crazy mother, or not a mother." (*Sarah, Mommy to Noah and Baby S.*)

While there are settings and situations outside the context of *Mommies with Hope* where women do not feel comfortable or able to talk about the children whom they have lost, they come to *Mommies with Hope* with the expectation to share and to listen. Kate describes her inability to talk to others about her loss experiences and how it is different at *Mommies with Hope* when she says,

"I almost feel like sometimes people view it [talking about her loss] as 'well you're just looking for sympathy,' when it's like, no, I just want you to know what's going on. So sharing it at Mommies with Hope...I wouldn't think twice about not sharing it, you know." (*Kate, Mommy to Will and Baby S.*)

Sarah echoes this notion by saying, "At Mommies I can share the memories and share the stories and everybody wants to hear and everybody wants to share." (*Sarah, Mommy to Noah and Baby S.*) Hannah also portrays *Mommies with Hope* as a "safe place" when she says, "It's a great support for you if you need to talk about your loss. It's a comfortable place to do that." (*Hannah, Mommy to Benjamin and Twin Boys.*)

Sarah describes her perception of support through *Mommies with Hope* as follows,

“...being *able* to share, being *able* to help, being *able* to relate to somebody else and somebody who’s maybe at an earlier stage of what you’re going through...it’s a safe place to talk about it.” (*Sarah, Mommy to Noah and Baby S.*)

She emphasized the “able” in her statement each time she said it. It was almost as if she is unable to do those things mentioned above (share, help, relate) in other settings. To her *Mommies with Hope* provides an opportunity for each of these things, and this is made possible because it is a “safe place.” When asked about her greatest source of support through her loss experiences, Hannah asserts, “I would say the group, Mommies with Hope, has been the greatest support, just because it’s so easy to talk about it here and everyone has encouraging words...I feel like that’s been my greatest support.” (*Hannah, Mommy to Benjamin and Twin Boys*). She attributes this due to the ease of being *able* to talk about her loss within the group. Ann shares a similar thought when she says, “it’s a safe place to come and be able to open up and share your feelings and your emotions.” (*Ann, Mommy to Baby H.*) Or, as stated in the words on the home page of our website, *Mommies with Hope* is a “safe haven of love and support.”

### *Sub-Themes*

The sub-themes that emerged throughout data collection and analysis specifically address how *Mommies* experience support by participation in the group and are comprised of the following: Receive Support over Time, Experience Validation, Build Friendship, Foster Christianity, and Able to Help Others. I have described each sub-theme in detail below.

#### *Receive Support over Time*

The need and appreciation for ongoing support has been echoed by women

throughout their participation in this study. They appreciate the fact that *Mommies with Hope* provides continued comfort and encouragement over time. Participation is not time-limited and there is no set curriculum to follow that prohibits women from joining at any time or that discourages them from continuing to participate. Elise makes the comment that reiterates the value of receiving support over time when she says, "...you never forget and your pain never goes away, you never get over it, you just learn to deal with it." (*Elise, Mommy to Dominic and Baby C.*) On a similar note, Elise goes on to say, "...just that monthly meeting, even to this day, even though it's been two-and-a-half years, it still helps me cope with my loss and adjust to the new normal of what life is." (*Elise, Mommy to Dominic and Baby C.*) Both Elise and Sarah participated in a hospital-based support group prior to the start of *Mommies with Hope*. They actually met at that particular group. The group that they had been attending, ended just a few weeks before *Mommies with Hope* began in the fall of 2007. Each of these women appreciated being able to find something that would be ongoing and not restricted to a limited duration of time, as was the case with the hospital-based group that they had met at. In fact, Elise was deliberately seeking out additional support while involved with the hospital-based group. She describes this process by saying, "afterwards [after Dominic's death] I did kind of seek out a support group...through the hospital is what we decided to do as a couple and after that I was still kind of in search of something ongoing." (*Elise, Mommy to Dominic and Baby C.*) Sarah elaborates on this seeking of ongoing support when she describes her experience with the same hospital-based group where she met Elise:

"The hospital group had finished maybe just a couple of weeks before that [before *Mommies with Hope* started], and had finished kind of abruptly. We didn't know it

was the last session when we had the last session. None of us did. So like, *Mommies with Hope* gave us the opportunity to get together for that one last session that we all thought we would have. “

Sarah is referring to the fact that the hospital-based group ended earlier than anticipated, as it was scheduled to go for six consecutive weeks. The abrupt ending of this group was disturbing to her and others involved in that group, but *Mommies with Hope* offered her, Elise, and some of the other women from their hospital-based group who came to that first monthly “hope” meeting an opportunity to provide some closure. Sarah and Elise have been coming ever since that first meeting, two-and-a-half years ago.

Women who come to the group are able to receive support over time by participating in *Mommies with Hope*. This opportunity to receive support over time is key considering many women receive messages from friends, family, or maybe even spouses that they should “move on” from their loss or “try again” with regards to childbearing. In fact, each of the women I interviewed for this study talked about the various clichés and messages they received from others. Hannah describes the message she gets from others by saying, “it’s [the loss] just not shared openly because people kind of shove it away, like oh well, we can try again.” (*Hannah, Mommy to Benjamin and Twin Boys*) Kate shares a similar statement when she describes her experience with those who have not experienced loss by saying, “I have gotten the feeling of ‘oh well at least it was early on’ or something like that.” (*Kate, Mommy to Will and Baby S.*) Such cliché’s, which I do think are well-intended on the part of the person stating them, tend to minimize the loss experience and magnify the need for women to receive support over time. Perhaps because women may not have had any support at the time of their loss. In talking about her recent miscarriage, Sarah asserts, “Some people

just kind of expect you to move on.” She goes on to describe her appreciation for the group by saying, “The clichés aren’t voiced in the group and that’s nice. It’s genuine, it’s thought out, it’s meaningful.” (*Sarah, Mommy to Noah and Baby S.*)

*Mommies with Hope* provides opportunities for women to receive support over time, and the women interviewed are citing this aspect of the group as important to them in their support experiences. That being said, it is important to also explain one key implication that I feel can sometimes be a hindrance to women’s support experiences, which is the fact that several of the women have gone on to become pregnant and/or have healthy children since their loss and remain involved with *Mommies with Hope* by coming to the monthly “hope” meetings and/or social events. This experience of a subsequent pregnancy after a loss is one that tends to be overshadowed with fear and anxiety from having experienced loss prior. It is as if the new pregnancy is tentative. We talked about this in great detail in a recent “hope” meeting. Some of the women were pregnant with a subsequent pregnancy while others were trying to become pregnant. Still others had gone on to have a healthy child after a loss, myself included.

Although women report feeling happy for those in the group who are expecting, and I believe that they are, there is also some feelings of discomfort amongst the group. I think that the subsequent pregnancies that are represented in the group can be difficult for those who are not pregnant and/or have experienced or are experiencing infertility. In general, women who have experienced loss tend to notice others around them who are pregnant. Kate describes her feelings about this very thing when she says,

“...and then losing Will, it was just like everybody else continues to be pregnant, you know. And I just remember at first looking at other pregnant women and just being

angry. Just so frustrated and upset, like why do I care? It was like they were throwing their bellies in my face, you know...I know they weren't but they were everywhere.” (*Kate, Mommy to Will and Baby S.*)

One of the women that participated in this study, Sarah, does not have any living children. Her first child lived for three days and died due to his diagnosis of anencephaly. Six months after his death, she and her husband started trying for another baby, but were unsuccessful. After a year of trying to conceive, they sought the assistance of a fertility specialist. After another year, on fertility treatments, without conceiving, Sarah finally became pregnant. Ironically, she conceived naturally, without the intrauterine insemination, which she and her husband had, in fact, done each month for the six months prior. Sadly, just three days after finding out about her pregnancy, she started to miscarry. It has been a challenge for her as she searches for meaning and purpose through this experience. Given the challenges she faces with becoming pregnant, coupled with her strong desire to have children, it can be difficult for her in the group, at times. She expresses some of this distress when she says, “I get so frustrated when others worry so much about it [pregnancy] when I’m thinking, you should be thankful for what you have.” (*Sarah, Mommy to Noah and Baby S.*) Likewise, Kate verbalizes a similar attitude when talking about her feelings of being alongside others who are expecting when she says,

“I would feel kind of resentful when she [a friend who was pregnant] would talk about it or complain about being morning sick and it’s like I wish I had that. And I had another friend that I found out we were due the exact same day and she’s complaining, ‘oh, I don’t feel good,’ and I’m like, well be thankful you don’t feel

good. You know? I'm like don't bitch to me about it." (*Kate, Mommy to Will and Baby S.*)

This dynamic in the group makes it a challenge, as a facilitator, to ensure a supportive environment for each woman present at our monthly "hope" meetings. Based on feedback from the women in this study and from listening to them speak about their support experiences, it has become necessary to think creatively about how to address this issue of subsequent pregnancies amongst women in the group. Such women have a unique need for support, amidst others who may be unable to conceive or not even thinking about trying for another child in the aftermath of loss. Sarah illuminates this very issue when she says,

"Sometimes have been harder than others, like when we started to realize that it was going to be hard for us to have more kids and we started going through the infertility treatments...that's hard. I mean that still is hard, just because it's so easy for some and then it's like, it just doesn't make sense why it's so hard, and it doesn't seem like it should be something that's so hard. So I think it was harder after we had that realization than beforehand." (*Sarah, Mommy to Noah and Baby S.*)

Practical implications of this issue will be discussed in further detail in Chapter 5 of this study.

### *Experience Validation*

As previously mentioned, both in the literature review as well as in some of the other findings, women who experience perinatal loss tend to also receive messages that devalue the significance of their child's life and their loss experience. Such was the case with the women who participated in this study, as illuminated by the various stories they shared. For these women, however, *Mommies with Hope* provided that validation. One of the women who

participated in this study, Ann, came to our group for the first time with the intent of supporting a friend. Her loss, a miscarriage at 13 weeks gestation, had occurred five years prior. When I ask Ann about her recollection of her first time attending *Mommies with Hope* she expresses her feelings of being validated through the group:

“...the very first time that I came and just the validation that I received from everyone and from you...the world just makes it like ‘Oh, you were just so many weeks along.’ And so I think that was very encouraging and probably one of the most memorable times.” (*Ann, Mommy to Baby H.*)

I go on to ask Ann about whether she had received any other formal support after her loss and she responds,

“No, there’s been nothing [other formal support]. And honestly, you know I always have felt like with this baby that it’s so many times just dismissed as you weren’t very far along, you know...No one’s come out and said it, but ‘Why should there be any issues? You weren’t very far along and you have other kids and you’ve had other kids since so why aren’t you fine? You should be fine with everything.’” (*Ann, Mommy to Baby H.*)

It was striking to me, personally, that it had been five years since Ann’s loss and she did not have any type of formal support offered to her during that time. She recalled no follow-up from her doctor’s office with regard to the emotional aspects pertaining to the loss. Still, five years later, she was able to come to *Mommies with Hope* and receive that validation for her loss experience, despite the fact that she initially came to support a friend. In her mind, she felt as though her friend’s loss was more significant, more difficult, or more traumatic. She



was, after all, “only just into her second trimester.” So coming to *Mommies with Hope* that first time was an opportunity for Ann to receive validation for her loss, as described below:

“I just remember that first night and after I had shared, and had been bawling to the point where I could hardly finish my story...I remember you saying right after that had happened, some type of comment that just totally made a calmness and made me feel at ease. I know you were speaking to me, but the way you worded it was like you were talking to the group and you just made a comment like ‘see how quick we are to put degrees of importance on each of our losses,’ I don’t remember exactly how you worded it, but just how they’re all important on their own and there’s not one that is more significant than another. I think that was just really when my heart started to open up and I was like this is good, this was good coming to do this.” (*Ann, Mommy to Baby H.*)

Through listening to the women in the interviews, focus groups, and in the actual support group setting, it became apparent that they receive validation for their loss experience and also feel as though their child(ren)’s life/lives are validated at *Mommies with Hope*. In settings outside of the group, women are bombarded with hurtful clichés that minimize the significance of their loss and/or devalue the life of their unborn child, particularly in the case of miscarriage. Elise talks about this very thing when she says,

“With a miscarriage, you don’t have any of that [tangible mementos/ memories], but the grief is still the same. I think a lot of times people just dismiss miscarriage and say ‘oh you can try again’ or ‘it wasn’t meant to be.’” (*Elise, Mommy to Dominic and Baby C.*)

Kate reiterates Elise's words regarding the minimization of miscarriage and the hurtful clichés that people use in such instances. In talking about *Mommies with Hope*, she states,

“I do think it is a safe place because everyone there has been hurt in some way or another and I don't feel like anyone is judging me when I talk about either loss. Regardless of how far along I was. It wasn't ‘just a miscarriage’. My baby meant something and the other women understand that as well. When talking to those who haven't experienced it I have gotten the feeling of ‘oh well at least it was early on’ or something like that.” (*Kate, Mommy to Will and Baby S.*)

Above, Kate proclaims, “It wasn't ‘just a miscarriage.’” She appreciates that women in the group understand and recognize her baby as more than “just a miscarriage.” Others also made comments about the acknowledgment received through coming to the group as well. For instance, Sarah describes this acknowledgment when she says,

“I feel like in that setting [Mommies with Hope] it's [loss] validated and it's viewed as a child and as a child in heaven and in that situation I know that our baby is recognized and cared about and that the loss is recognized and cared about it and it's not just a ‘oh you can try again’ or ‘oh at least you got pregnant’...I think there's a lot of validation in the group because they focus on the baby and the loss rather than what's next of what's around the corner.” (*Sarah, Mommy to Noah and Baby S.*)

The women view their loss as the loss of a child, a baby, a person. They are thankful that others in the group also view their child as a child. Many of the women expressed feeling like others outside of the group or those who have not experienced a similar type of loss do not consider the unborn baby as a child at all. Sarah verbalizes this idea when she says, “A lot of people don't recognize it as a baby...[to them] it's an early loss, there must not have

been much of a connection.” (*Sarah, Mommy to Noah and Baby S.*) Ann elaborates on this notion when she talks about her miscarriage at the end of her first trimester, giving meaning to the impact that her unborn baby had on her life.

“I carried this baby for almost three months and it just becomes such a apart of you and you’re so sick and then like all the sudden one day just to have all of that be gone...it’s just very, very difficult (tearful).” (*Ann, Mommy to Baby H.*)

Later, Ann goes on to say with regard to her miscarriage, “...you just feel like you for some reason don’t have the right to be grieving.” (*Ann, Mommy to Baby H.*)

The women in the group are recognizing the significance of the loss, and not only that, but they are viewing the child lost to miscarriage, in particular, as a child. They see that child as a baby and as a person, nothing less. They place the same value on that child’s life as the mother herself because they have each been through it and know the pain firsthand. Hannah describes her feelings of validation from the group when she shares the following:

“I think it’s [Mommies with Hope] definitely validated my losses. Like when other people [in the group] say Benjamin’s name, that kind of brings it more to life and then people ask me about the twin and just makes it seem like, oh that really did happen. I really have three children.” (*Hannah, Mommy to Benjamin and Twin Boys*).

Above, Hannah describes the acknowledgment she receives in the *Mommies with Hope* setting, both for her loss experience and for her children’s lives. She, like others who participated in this study, feels a sense of recognition, both for her grief and for the very reality that she is, in fact, a mother.

#### *Build Friendship*

Each of the women who participated in this study noted the significance of the friendships that have been formed with one another through participation in the *Mommies with Hope* support group. While some women were friends before coming to the group, as is the case for those who attend the same church or work together, others come to the group not knowing anyone beforehand. The latter was the case with Renee, who speaks highly of the fact that the group has been a way in which she has made friends. Renee moved to the area from another part of the state and did not have many friends nearby, apart from those she had come to know through her work in an elementary school. She credits *Mommies with Hope* as an opportunity to meet new people, including other women who have experienced perinatal loss as well in addition to other couples, given the fact that we occasionally have couples social events. Furthermore, Renee reports feelings of belonging through the friendship's she's made in the group when she says, "I really like the social aspect of the group. I like coming and hearing people say, 'Oh, Renee's here!'" Kate concurs when she explains her reason for coming to *Mommies with Hope*: "I came to Mommies for comfort for my losses and to find camaraderie." (*Kate, Mommy to Will and Baby S.*)

Not only do women have the opportunity to meet new people and build friendships, but they get to know one another beyond their loss experience through the social support component of the group. At the monthly hope meetings, our time is focused primarily on issues related specifically to the women's loss experiences. The women who participated in this study agree that providing opportunities to meet outside the context of the support group setting, in a more social outlet, as women and as couples, is beneficial to the group as a whole. For instance, take the words of Ann as she describes her feelings about this notion:

“I had a blast doing that [concert social] and I felt like that was fun because I was able to connect with a few of the ladies on a social level. When we have the meetings we sit around and talk and it’s just more of a laid back setting...With socials, I think you get to know people on a level beyond their loss. When we’re at Mommies it’s great, but that’s what we’re there for – support and encouragement for one another’s losses.

So it is fun just to do something fun too.”(*Ann, Mommy to Baby H.*)

Sarah goes one step further in connecting the socials and the friendships that are built through this aspect of the group by saying, “I think being able to develop those friendships makes the group stronger when we come back together to talk about our losses.” (*Sarah, Mommy to Noah and Baby S.*) Elise states something similar when asked to describe the group in her own words by saying, “...we also have social events on the side, so you know we’ve built those strong connections and it’s nice to be able to continue to foster those relationships as we’re a part of the group.” (*Elise, Mommy to Dominic and Baby C.*) Sarah’s words reiterate this facilitation of building relationships when she says, “There are definitely connections and relationships built from that [participating in the group].” (*Sarah, Mommy to Noah and Baby S.*)

### *Foster Christianity*

Given that *Mommies with Hope* is a biblically-based support group with a mission that states, “Called to reach grieving women for Christ, providing comfort and encouragement rooted in Scripture” it is expected that the findings would illuminate some aspect of spirituality. The women who attend the group typically find out about the group from a friend, medical professional, or through a local community resource booklet, which results in them visiting the *Mommies with Hope* website and/or blog and then emailing to

inquire about the group. The website, blog, brochures and descriptions available to the public openly state the Christian basis of the support group. Thus, women who attend the group know before they come that the group has a spiritual foundation. To date, the women who have attended have all been open to the fact that the group's Christian mission. Currently, there is a range of Christian denominations represented in the group, including Protestant denominations of Evangelical Christian, Methodist, Lutheran, Baptist, as well as some women who are actively involved in the Catholic Church.

For some women, the inclusion of spiritual aspects is a major part of their initial and continued attendance. Tia found out about our group through a Pastor whom she met at a local hospice where she volunteers. She was particularly interested in the fact that the group included aspects of spirituality in helping support women through their loss experiences. She states, "I've been to previous groups, like \_\_\_\_\_, and I didn't know what bothered me so much about that group, but it was the fact that God wasn't mentioned." (*Tia, Mommy to Ryan and Grace and Baby S.*) Tia goes on to express the role that God plays in her coping with her losses when she says, "The primary thing that helps me get through this is God, seeing where God comes into play. That's what makes me want to keep coming back [to Mommies with Hope]. (*Tia, Mommy to Ryan and Grace and Baby S.*) Elise mentions something similar when she talks about the biblical basis of *Mommies with Hope*, by saying

"...the fact that it [the group] had that biblical element to it really intrigued me and I really wanted to be a part of it as I continued to heal from our loss. I just really thought that that was a way for me to kind of cope with my grief and as I put it, kind of get back on track with God because I did have some really mixed feelings that I

needed to reconcile with Him and this group has really helped me to do that.” (*Elise, Mommy to Dominic and Baby C.*)

Sarah also places great significance on the spiritual components of the group. More specifically, she alludes to the meaning and purpose behind her losses when she talks about the role that the bible plays in her experience with *Mommies with Hope* when she says, “Being biblically-based...that’s huge. When God’s involved it’s just, you know it’s not for nothing. You know it not just to cause you pain and grief and you know there’s something else there. (*Sarah, Mommy to Noah and Baby S.*) At another point in one of our interviews, I asked Sarah what has been the most helpful to her in her loss experiences and she confidently proclaims, “...definitely being saved and having Christ was the most helpful.” (*Sarah, Mommy to Noah and Baby S.*) Kate’s words resonate this notion when she asserts,

“I have no doubt I would have recovered as quickly as I did without having God to help me through it. It brought me closer to Him than I had been in years. Relying on the Lord was a big part in my recovery.” (*Kate, Mommy to Will and Baby S.*)

Related to the thoughts shared by the women above, Ann offers insight from her perspective as to the benefit of being a part of a Christian-based support group. She states: “I think believers [Christians] have something else to offer and that’s the hope of Jesus and the truth go where the child is. You know that is just a comfort and you know it’s a peace that surpasses all understanding.” (*Ann, Mommy to Baby H.*) To Ann, the fact that the group is based on biblical principals is key because she is able to receive “hope” and “peace” that she does not believe to exist outside of Christianity. On a similar note, Tia suggests the need to examine her losses in such a manner when she says, “The substance of life is God and

love, so how could you leave it out of this? I honestly do not feel like people could maintain their sanity after this type of a loss without God.” (*Tia, Mommy to Ryan and Grace*).

For others, the spiritual component of the group is not as instrumental and at times can be uncomfortable. For instance, Renee states, “It can be uncomfortable at times...I feel like I don’t have as much wisdom or know the bible like others.” (*Renee, Mommy to Owen and Ellie*). When talking about the aspects of spirituality of the group, Renee brings up an activity that we did in a recent “hope” meeting. It was a more structured incorporation of scripture references from the bible designed to engage women with the passages and apply them to their current grief struggles. With regard to this particular activity, Renee goes on to say, “I was excited to see that I could read the bible and understand what it meant and apply it to my situation. I felt like ‘hey, I really do know something.’” (*Renee, Mommy to Owen and Ellie*). So while Renee reported feelings of “discomfort” pertaining to the spiritual components of the group, after further probing, it became more evident that the discomfort was a result of a perceived lack of biblical wisdom in comparison to other women who participate in the group. We talked about this in the focus group setting as well, and one other woman, Elise, also reported similar feelings. Each, however, appreciated and desired the incorporation of spiritual components. These findings, however, do provide insight into some practical implications for improving this aspect of the group, which will be discussed in more detail in Chapter 5. It is important to note that both Renee and Elise, the two women who reported feeling “uncomfortable” at times, assert that the benefits of being a part of *Mommies with Hope* outweigh the sporadic moments of discomfort in the group setting, and therefore, they continue to come and receive support.

Women who participated in this study indicated that they have experienced spiritual



growth by participating in the group. Tia describes her quest for understanding her losses through a spiritual lens and how *Mommies with Hope* has aided in her search for answers by saying,

“...that has been the biggest struggle for me throughout all this...trying to understand how God comes into play and where God is through this tragedy and the fact that this is biblically-based and you read a lot of Scripture and read out of the bible. I’ll never fully understand it but it helps me to come to term and accept it. So I think that the mention of God really helps and just getting things in the bible that pertain to this type of loss.” (*Tia, Mommy to Ryan and Grace*)

Hannah acknowledges this quest for understanding when she says, “...hearing that word that we are one day going to see our children, I had never even heard that before so that has definitely validated that I’ll get to see my boys again.” (*Hannah, Mommy to Benjamin and Twin Boys*). She later asserts, “...the encouragement through the Word [bible] has helped me tremendously...I’ve really grown a lot through that in this group and it has helped me deal with my feelings about the losses.” (*Hannah, Mommy to Benjamin and Twin Boys*).

Women who participated in this study commonly referred to the idea that God has a plan for, both for their children’s lives and for their own life. In a way, they were agreeing with the common cliché that “everything happens for a reason”, but would openly admit that hearing such words from others has not been particularly helpful at times, as averted to previously. I bring it up here, however, because while women may express feeling devalued by hearing such a cliché from others, they also find comfort in the idea that “God has a plan.” For example, Hannah tearfully expresses this belief in the following words:

“I realized that everyone goes through trials and I just feel like this is the path that God has chosen for me, so I mean there’s nothing I can do about it because it’s in His plan so I just feel like there’s no reason to be down about it anymore. It hurts, but what are you gonna do? It just the way your life was planned out.” (*Hannah, Mommy to Benjamin and Twin Boys*)

Similarly, an anonymous woman posts a comment to the *Mommies with Hope* blog that echoes Hannah’s thoughts. This anonymous woman says,

“We lost a baby to miscarriage in September of 2008. It was a difficult time. Hard to understand, but so thankful that I had such peace and hope in knowing that God is in control, He has a plan and I can trust that plan.” (*Anonymous*)

Each of these women are trusting that God was in control of the situations they were facing in the midst of their loss experiences. I can personally relate to this belief of God being in control, as I have rested in this very belief through each of my own losses. Like the other women, I do believe that there was a plan a purpose to those babies’ brief lives. One such purpose I have been able to find includes the very fact that *Mommies with Hope* exists.

Without having ever experienced loss, I would have never had a desire start the group in the first place. As described in more detail in Chapter 3, the co-founder, Jen, and I started the group with the intent to comfort others the way we ourselves had been comforted by God, based off of a scripture verse found in the book of 1 Corinthians. Ann acknowledges this same idea through her own experience when she says,

“I feel like maybe the Lord wants to use me to help support other women who have gone through very similar circumstances as I’ve gone through. And I feel like since

I've come, there have been women with those same circumstances. And so I think even that the Lord just may be using me in that way." (*Ann, Mommy to Baby H.*)

Ann places purpose behind her loss as she acknowledges her belief that God is "using" her to help others.

Finally, each of the women interviewed in this study indicated in some way that they held the belief that their child was in heaven. Women found great comfort in this idea and spoke about their longing for heaven as well and the confidence in the belief that they would see their child again. Consider Ann's words as she describes her feeling about this very notion:

"...just knowing that that baby that I lost is in heaven waiting for me is just amazing for me to think about. That tells me right there that that baby was important and that God did have plans for that baby, and that really helps to just kept that baby's spirit alive within me, just holding on to that bond." (*Ann, Mommy to Baby H.*)

Elise reiterates this very thought through her words, which state, "I think it's [loss] definitely caused me to look at life a different way and to realize all the blessing that we have and just that reassurance that I will see him again because of what Jesus did for us." (*Elise, Mommy to Dominic and Baby C.*) Elise is referring to the Christian belief that Jesus died on the cross as a sacrifice for sin, to make a way for those who believe in Jesus' sacrificial death to enter heaven upon physical death.

Since *Mommies with Hope* is a Christian-based support group, the ideas of heaven and the afterlife are topics that are discussed frequently at monthly "hope" meetings as well as in other methods for providing support such as through the blog, website, and book resources for example. The belief that these children are in heaven provides great comfort

and peace to the women. Sarah refers to the significance of such a belief when she talks about the comfort she receives in acknowledging that Noah would go to heaven upon his death when she says, "...the promise that when Noah would die that he would be in heaven and that he was going someplace peaceful where he would be safe and loved and healthy." (*Sarah, Mommy to Noah and Baby S.*) As you may recall, Sarah knew halfway through her pregnancy that Noah would die shortly after birth due to his diagnosis of anencephaly. Thus, she found great hope in the assurance that he would go to heaven upon his death. Kate also acknowledges her belief that she will be reunited with her children she has lost to miscarriage when she says, "It is such a blessing to know that I will see my babies in Heaven one day! Knowing that they never had to suffer here on earth and they know only Heaven is a really cool thing." (*Kate, Mommy to Will and Baby S.*) These women have a hope that extends beyond their physical lives. They believe in an afterlife where they will be reunited with their babies who died. *Mommies with Hope* is entitled as such due to this very core belief in a heavenly afterlife, central to Christianity. When I asked Elise about her view of the spiritual aspects of the group, her response encompassed many of the ideas described above:

"...just to know we're receiving comfort about what happened and to be able to tie that back to Jesus' purpose for being on this earth and ultimately find meaning through loss as well...so just to be able to tie that back to our relationship with God and the whole reason for Jesus' coming into the world and that reassurance that we'll see our children again in heaven." (*Elise, Mommy to Dominic and Baby C.*)

The women who participate in *Mommies with Hope* are growing in their spirituality and embracing a peace and a hope found in Jesus Christ, as evidenced in their remarks above.

*Able to Help Others*

Participating in *Mommies with Hope* provides opportunities for women to mutually support other who have experienced loss. As described in more detail above, under the encompassing theme of “Our Hope Stories: Linked by Loss,” women are able to make connections with others in the group who have experienced situations similar to their own. While everyone has experienced some type of loss, there is still a range of losses represented in the group. Thus, when women come, it is crucial to share our stories so that similar situations can be identified and we can facilitate connecting women with one another. The women who participated in this study noted the significance of not only sharing our experiences and connecting with women who have been through something similar, but using that information to then be able to reach out and help someone else. *Mommies with Hope* provides this opportunity and women appreciate that aspect of the group. Consider the words of Elise when she describes this pay it forward approach to support:

“Some of the more seasoned members can actually minister to them [newer women] and be of comfort to them and support to them. That’s really a great kind of benefit of continuing to come back to the group. So you’re not only benefiting yourself, but you’re able to turn that around and help others too.” (*Elise, Mommy to Dominic and Baby C.*)

In this statement, Elise is describing her experience with being able to give and receive support through *Mommies with Hope*. I have observed each of the women “give back” in their own way through the group. For some women, it includes the simple gesture of offering to bring treats for a monthly “hope” meeting and for others it may be reaching out to invite a co-worker or neighbor who recently experienced loss that they would like to be able to support.

Ann describes her desire and willingness to help other women that have experienced loss when she says,

“I want to be able to just open my arms and let women know that there are people that love them and want to help them through these things. I want to be able to be used as an encouragement for others.” (*Ann, Mommy to Baby H.*)

She goes on to confirm Elise’s statement above regarding the benefit of continuous participation in the group when she says, “...coming back to *Mommies with Hope* offers opportunity to minister to others.” (*Ann, Mommy to Baby H.*) Kate also expresses her desire to help others by saying, “I almost feel like I’m at the point where I would be maybe of more use helping someone else. If they needed someone to talk to, or just listen to.” (*Kate, Mommy to Will and Baby S.*)

It is necessary to make note of the fact that the women who participated in this study are women who have consistently been a part of *Mommies with Hope*, some of which have come from the inception of the group, as previously mentioned. This fact may contribute to women’s desire to help others. *Mommies with Hope* then offers the platform for which they can help others.

Examining women’s perception and experience of support through *Mommies with Hope* unveils the disenfranchisement of their perinatal loss experiences in a number of ways. Women admit that there are “unsafe” places outside the group where they are not free to talk about their child who died or their feelings surrounding that loss. Women feel isolated and alone in their grief, outside the context of the group. Having the opportunity to come to a safe haven for support with others who’ve “been there” and where the silence is broken, is an outlet for women who have experienced perinatal loss. In some cases, support extends

beyond the walls of the support group through the friendships that are built. I have experienced this support firsthand, whether it be through a friendly email, phone call, or invitation for coffee. These women, linked by their losses, have grown to love and care for each other in ways others cannot. For them, they now have a safe place to talk and a group of women to share with. They feel that their children and their experiences are valued and important. Still, the very fact that these support experiences remain confined to a place, *Mommies with Hope*, exposes perinatal loss as a disenfranchised grief, experienced silently on the margins of society. Yet, this is a start. At least now, they are not alone.

### *Discussion*

Evidenced by the findings from this study, much can be learned about the way in which mothers experience support through a formal support group like *Mommies with Hope*. Approaching this research through a critical lens, acknowledging the disenfranchisement of perinatal bereavement and interpreting the data as such, it became apparent that women valued participation in the support group setting – a safe place where they had a voice, where their child's life and the experience of loss mattered, and where they could receive support. The encompassing themes and sub-themes that emerged from the data resonate with the current literature on the phenomenon of perinatal loss and support, or lack thereof, which is addressed in further detail below.

The encompassing themes, 1) Our Hope Stories: Linked by Loss, 2) Silence is Broken, and 3) *Mommies with Hope: A Safe Haven*, each addressed the issue of perinatal bereavement as a form of disenfranchised grief. According to Bennett and colleagues (2005), the lack of recognition and discounting attitude of society often leaves the parents feeling isolated and distraught during times of perinatal loss. This is just one example of the

disenfranchisement of these women's grief experiences. Further, Cacciatore and colleagues (2008) recognize that stillbirth as an "invisible death," meaning that others often tend to ignore that it ever occurred and do not clearly see that stillborn child as a member of the family to whom he or she was born. They used Boss's (2001) framework for ambiguous loss to understand stillbirth in families.

Women in this study indicated that they are "able" and "comfortable" to talk about their child and their loss at *Mommies with Hope*. Thus, the group is seen as a safe place to talk and the silence is broken. Women reported feeling isolated and alone in their grief, outside the context of *Mommies with Hope*. This is consistent with Harvey's (2001) findings, which showed that silence, isolation, and loneliness are common to miscarriage experiences of women. At *Mommies with Hope*, however, women reported feeling safe and comfortable talking about their losses. One primary reason this is able to happen is because of the shared experience of loss that binds these women. Consistent with the literature, Hutti (2005) suggests that support is most credible to bereaved parents when it comes from a person who has had a similar experience and has managed to deal with the situation effectively. Women in the current study reiterated this point when they talked about the comfort of being around other women who have "been there" and have come out on the other side. It gives them hope.

Regarding the sub-theme, Receive Support over Time, women emphasized the importance of being able to count on an ongoing source of support for their loss. In particular, women appreciated remembrance of special days such as birthdays, anniversary dates, due dates, etc. Cacciatore and colleagues assert the need for ongoing support in cases of perinatal loss when they state, "the bereaved live with loss and manage loss, but loss



remains a part of grieving parents forever” (Cacciatore et al., 2008, p. 441). Romesburg (2004) echoes this notion when she describes parents’ reports of their grief as becoming “different” over time, rather than ever “getting better.” Each of these findings were supported by the findings in the current study, indicating the need for ongoing support.

An effect of women receiving support over time is that some women also experience subsequent pregnancies after loss as time goes on. As a result, it has become apparent that this dynamic in the *Mommies with Hope* group may cause undue stress for some of the women who participate due to the differences in these women’s current grief challenges. One woman may have experienced loss and subsequent infertility while another may have experienced loss and is now pregnant with a healthy child. Each woman’s experience is valid in her own right. The woman struggling with infertility, however, may have a difficult time coming alongside a woman with fears and anxieties over a healthy pregnancy. Such anxiety does exist among women who experience a subsequent pregnancy after loss. In a study on ambiguity and stillbirth, Cacciatore and colleagues (2008) found that women experienced a great deal of uncertainty after loss. These feelings of uncertainty extended into future pregnancies (Cacciatore et al., 2008).

A major finding that surfaced in the current study is the sub-theme, Foster Spirituality. Women’s experiences of support through *Mommies with Hope* in light of the spiritual nature of the group reflected four major areas in which the group helped foster spirituality. The first is that women placed significance on spiritual components in their receipt of support. This aspect of the group was important to them. However, differences in religious beliefs or knowledge influenced the way in which spiritual support was experienced in *Mommies with Hope*. Two women reported feelings of “discomfort” at times, based on

their reported lack of biblical knowledge in comparison to others in the group or the fact that their faith community did not encourage the reading of the bible for oneself. Tedeschi and Calhoun (2006) indicate that bereaved individuals may come to rely on their religious communities and the response they get from their community may impact the role in which that opportunity for support plays in the bereaved person's life. In light of this, it is important that *Mommies with Hope* strive to embrace each woman and her comfort level with the spiritual nature of the group. This has been addressed on several occasions in my facilitation of the group as well as with individual women.

Secondly, women reported experiencing a welcomed spiritual growth by participating in *Mommies with Hope*. Women indicated contemplating the “why” questions about the loss of their child(ren). Such question is a typical response of the bereaved, which is a result of trying to understand the occurrence of a death that may not fit with one's initial conception of God (Tedeschi & Calhoun, 2006). Thus is the case in *Mommies with Hope*, as women seek to reconcile their beliefs with the tragedy of a seemingly senseless loss. On a similar note, DeSpelder and Strickland (2008) discuss the use of bereavement as an opportunity for growth by stating, “Becoming a survivor can allow for changes in beliefs and values – understanding about death and about life – that might not have been possible otherwise” (p. 346).

Also, women indicated a belief that God had a plan through their loss experiences. While they did not understand everything completely, they did believe that there was purpose and meaning behind their children's brief lives. This notion resonates with the findings from a study conducted by Redlinger-Grosse and colleagues (2002). In their study, parents were faced with a prenatal diagnosis of holoprosencephaly, a terminal condition, for their unborn

child. With regard to decision-making in light of this situation, they did so in terms of their belief in God or religious beliefs. Many of the women in this study felt that it was “God’s plan” or that it “happened for a reason” (Redlinger-Grosse et al., 2002, p. 372). Finally with regard to spirituality, women expressed a confidence that their baby was in heaven.

According to Tedeschi and Calhoun (2006), “attention to the understanding of death and a possible afterlife become critical” (p. 109). At *Mommies with Hope*, we aim to provide that understanding from a biblical perspective, of which the women in this study have reported is of great comfort to them in their grief.

Regarding the sub-theme of Experience Validation, women reported feeling as though their grief experiences were acknowledged in the *Mommies with Hope* group. Women indicated feeling that their children’s lives and their loss experience were valued and validated. To fully convey this perception of support, women also indicated many instances of non-supportive contexts and experiences that have discounted their child(ren) and their grief experiences. Sometimes this perceived lack of support came in the form of silence, meaning that others did not acknowledge or recognize the loss. Such reports of silence are consistent with findings of St John and colleagues (2006) who assert that silence is a common response to loss and the pain of the loss is not legitimized by society, leading to a woman feeling isolated (St John et al., 2006). Women in the current study indicated that they felt alone outside the context of the group, but at *Mommies with Hope*, they knew that they were “not the only ones in the world” (*Hannah, Mommy to Benjamin and Twin Boys*) who had gone through such an experience as perinatal loss. In addition, women also reported feeling as though they had to offer comfort to those around them who reacted negatively to news of their loss. This idea of comforting the comforter turned the tables from the

expectation of comfort that women desired from others. Instead of receiving comfort from those outside of the context of the group, women were often offering solace to those individuals who were shocked to hear of their loss. In turn, women refrained from sharing about their deceased children in an effort to avoid this kind of situation, thereby experiencing their loss in further silence.

The final sub-theme, Able to Help Others, links to the encompassing theme of Our Hope Stories: Linked by Loss in that because of this shared experience of loss, women who have “been there” are able to help others. This circulation of support exists based on the fact that others have experienced something similar. *Mommies with Hope*, then, offers a platform for women to continue on that support, whether it be by inviting a newly bereaved co-worker or friend, or welcoming a stranger to the group whom we are instantly connected or through our shared experience of loss. Such connections, subsequently contributed to the building of friendships, another sub-theme of this research.

An important point of discussion drawn from the findings of this study is that comfort stems from women’s receipt of support over time, which was a sub-theme of the research mentioned above. While women benefit from the ongoing provision of support and the grief truly never ends, the question of how to continue to provide support, particularly through a subsequent pregnancy, comes to light. This matter will be discussed in greater detail in Chapter 5.

### *Limitations*

Findings from the current study, detailed above, provide a research base for *Mommies with Hope* and offer insight into support provision for professionals, support group leaders, and ministry leaders. The practical implications of these findings will be discussed in greater

detail in Chapter 5 of this study. It is also necessary to note the limitations of the study. An important limitation is the small sample size, consisting of seven women total. This is, in part, due to the fact that *Mommies with Hope*, though growing, is a relatively small group overall. Since the study focused on how women experience support for their loss through *Mommies with Hope*, it was expected to be small given the size of the group.

Related to the sample, each of the women who participated in this study was married, Caucasian, and a self-proclaimed Christian. Thus, the sample was homogenous. However, this again is determined by the make up of the group in general. It was expected that the women be Christian considering *Mommies with Hope* is a biblically-based support group and is promoted as such. It would be interesting to pursue future research that investigates the spiritual aspect of the group, specifically. While findings from this study indicated that spirituality was important in women's support experiences, this theme could be expanded upon in various ways. Further, racial diversity would enhance study on this topic, as it may uncover differences in how women experience support in contexts outside of the *Mommies with Hope* group, such as through family or friends.

Another limitation of the study is that one woman participated in one of the focus groups, but not in the individual interviews. This woman, in particular, joined *Mommies with Hope* after data collection and analysis had formally begun. However, her continued participation in the group led me to invite her to the second focus group, which she did in fact attend. I did not invite her to participate in the study in any capacity prior to that because, in my opinion, she was not emotionally ready. In continued research, she would be a person I would ask to participate.

Finally, further exploration of the topics at hand could include father's experiences and the experiences of siblings and/or other family members. *Mommies with Hope* does not formally offer support for fathers, though we do occasionally have social events where fathers are welcomed. It would be interesting to explore their perspective on support through *Mommies with Hope* both for their wives and for themselves. Another area not specifically addressed in this particular study, though it surfaced in our monthly meetings and throughout this research process, was the disenfranchised experiences of women who place a child for adoption or who have undergone abortion. These two phenomena would be further areas of investigation. I did not focus on these types of loss, though they were represented in the group.

## CHAPTER 5. CONCLUSIONS

### *Summary*

Society often fails to recognize the significance of perinatal loss and the intense grief reactions experienced by mothers who endure such loss (Drake, 2008). By critically engaging with the phenomenon of perinatal loss support through the current study, I aimed to gain greater understanding as to how women experienced support and validation for their loss experiences. Specifically, the purpose of this critical ethnography was to explore the support experiences of mothers who participate in the *Mommies with Hope* support group. Through observations and interviews, as well as through feedback given in two focus groups, I found that mothers revealed several ways, described in great detail in Chapter 4, in which they actually experienced support through the group.

We can look at this list of themes and sub-themes and perhaps think to ourselves, “Isn’t it a given that women would be supported by others who have been through something similar? Shouldn’t they be able to talk to each other, no problem? Of course they receive support over time and become friends...they meet together every month.” Each of these remarks posed above is true. Women who come to *Mommies with Hope* have experienced perinatal loss. They share with each other. They meet every month and sometimes more frequently than that. They become friends. Still, there is much more to it than a mere list of themes and sub-themes. The very fact that women indicate that at *Mommies with Hope* they feel “safe” to talk about their losses or that they are “able” do so “freely” and “without judgment” places a whole new meaning on their support experience. Mothers indicated that while *Mommies with Hope* is safe, there are places outside the group that are not – sometimes in the circles of their very close friends or family.

Doka identified three primary ways by which grief can be disenfranchised, which happens when the relationship, the loss, or the griever are not recognized (Doka, 1989). That is precisely what these women experience through perinatal loss. The relationship between mother and child in instances of perinatal loss is minimized tremendously, as is the loss experience itself. As you heard from women in the findings of this study, others often make comments like, “you can always try again” or “at least you can get pregnant,” both of which greatly diminish that a relationship even existed between that mother and her unborn child. When loss occurs, others tend to discount the grief and they approach the situation as if no relationship existed in the first place. In turn, the woman, or griever, is not recognized as a griever at all. After all, “why should there be any problem?” as stated in the words of Ann. (*Ann, Mommy to Baby H.*) That is the message we send these women.

Contrary to the disenfranchisement described above, typical of women’s experiences in general, women in this study indicated that *Mommies with Hope* offers them an outlet, a safe haven of love and support where all are welcome. The woman’s role as a mother is validated, regardless of whether she has any other living children. Her child’s life is validated and recognized as such – a child, person who meant something. Losses are not compared and each woman’s experience is valid and significant, yet unique in their own way. At *Mommies with Hope* women, the grievers, receive acknowledgement for who they are, the child(ren) they have lost, and the grief as real. Silence is broken and compassion sets in, welcoming women into an environment of safety where sharing about their experience of loss is expected and accepted.

Realizing that women experience support through *Mommies with Hope* in these ways contributes to an even greater understanding that aids in our ability to continue to provide



support to grieving “mommies.” Such information assists with the current and future support endeavors of *Mommies with Hope*, specifically, but also offers insight to other formal and informal support providers. We can use this information to inform healthcare professionals, clinicians, support group leaders, church and/or women’s ministry leaders, and lay people about the ways in which women experience support, which leads to the implications of this research.

### *Implications*

As previously mentioned, it was my goal to gain an understanding as to how women experienced support through *Mommies with Hope*. Such understanding aids in uncovering practical information that will not only serve to enhance the way in which the *Mommies with Hope* support group provides support, but also offers useful suggestions for others who find themselves in the support-giving role to women who have experienced perinatal loss, a very practical implication that will be described below. In addition, the current study establishes a research base, specifically with regard to the *Mommies with Hope* support group, but also contributes more generally pertaining to perinatal loss support, spiritual facets of perinatal loss, and perinatal loss as a disenfranchised grief.

### *Praxis*

Based on the findings from the current study, there is a great deal of information to disseminate and use for praxis, some of which has already been implemented in the current *Mommies with Hope* group that I co-facilitate. For example, women reported that they find support in the friendships that are built through the group and they appreciate the spiritual component. A month can be a long time to go between meetings, and therefore, we have just recently implemented an optional and supplementary bible study option for women to meet

outside of our regular monthly “hope” meeting. This new addition to the group addresses each of these two aspects described above. Another example also deals with the spiritual facet of the group. Some women reported feeling “uncomfortable” at times, given their lack of biblical knowledge compared to others in the group. Thus we have shifted from completely open-ended discussion and sharing for the entire duration of our meetings to incorporating a 10-15 minute “teaching” component, engaging women with a structured activity for greater depth of understanding, leveling the playing field in a way.

In addition, during the process of completing this study, a second *Mommies with Hope* group in a nearby community was established. In the initial training and ongoing support of and collaboration with the facilitators for that group, I have employed the findings from this study to inform and guide that process. It seems necessary, then, to utilize the findings from this study to assist in the development of an official training manual or guide for prospective *Mommies with Hope* facilitators for additional support groups, which will be an endeavor that I plan to pursue in the near future.

There are some other very practical implications for those who wish to start support groups, apart from *Mommies with Hope*, for mothers who have experienced perinatal loss. Acknowledging that *Mommies with Hope* is a biblically-based group, I realize that not all bereaved women seeking support would be interested in such a group. Still, it would be a disservice to these women to refrain from sharing the information gleaned. Rather, it is necessary to share these findings, which provide valuable information for the creation of secular support where needed. Admittedly, women in this study placed a great deal of importance on the spiritual aspect of the group, both in how they receive and experience support as well as citing the spiritual facet to the group as that which keeps them coming

back. That being said, there may be women who could benefit from a perinatal loss support group, but the spiritual component to the group does not align with their personal beliefs, thereby keeping them from ever attending. While *Mommies with Hope* exists with an deliberate Evangelical Christian mission, the findings from this study can still inform other practitioners, clinicians, professionals, and lay people alike in how they can offer support to women from a secular worldview. Furthermore, it is feasible to create resources or materials for use in hospitals, funeral homes, or other secular institutions that offer bereavement support for perinatal loss based on the findings from this study. It is important that supportive resources and information are made available to *all* women who experience perinatal loss, regardless of their religious beliefs. To limit the dissemination of these findings would only serve to perpetuate the disenfranchisement of these women who I so eagerly wish to liberate as they suffer silently in their grief.

#### *Future Research*

As previously mentioned, the current study initiates a research base for *Mommies with Hope*. Such a basis encourages future research by potentially uncovering further research questions or phenomena to explore, including topics such as fathers' experiences, subsequent pregnancy support, and exploring issues of spirituality further, each of which are be described in more detail below. Utilizing findings from the current study aids in our goal of establishing additional support groups in other communities by offering valuable information about what women find most helpful in our provision of support through *Mommies with Hope*.

Evident from the findings of this study, various topics need further exploration. Of particular interest are those issue surrounding spirituality and women's perinatal loss and

support experiences. Women cited spirituality as an important tool for understanding and coping with their losses. However, some reported feelings of discomfort or intimidation when it came to the bible. It would be interesting to investigate the denominational differences and how these correlate with women's comfort level with the bible and/or using the bible as a resource in the support group setting. From pure observation, it was apparent to me that the Catholic vs. Protestant views represented in the group posed a unique facet to the group and the discussion that ensued. I would be interested in hearing more from women about their doctrinal beliefs and how these beliefs influence their perinatal loss experiences and experiences of support. On a similar note, it would also be worthwhile to investigate if and how churches and/or women's ministries formally address this women's issue in their congregations. Churches often have numerous ministries to meet the needs of their congregation, including needs such as marital counseling, topical bible studies, groups for young parents, ministry for the ill, etc. Considering the prevalence of miscarriage, one may assume that this is addressed in churches. Or, maybe it is swept under the rug, just as it is in society.

Additionally, it would be interesting to explore fathers' experiences with perinatal loss, viewing it through a critical lens as a form of disenfranchised grief. Even more often than mothers, I believe fathers get overlooked in such situations and are expected to protect their partners through the loss experience, thereby ignoring their own grief. In *Mommies with Hope*, we sometimes invite the fathers to join us for occasional social outings. While we typically do not delve too deeply into grief and loss support at social functions, the mere presence of one another extends an aspect of support for fathers. It would be interesting to explore fathers' perspectives on *Mommies with Hope* and their wife or partner's participation

in the group. In the past, we have been asked whether a group is available for men through *Mommies with Hope*. While we do not formally offer such a group, there is apparently a need and desire, which is an aspect for future study and praxis.

Related to the formation of another group brings forth the idea of creating a separate group to support women who are coping with a subsequent healthy pregnancy after loss. Currently, women are welcome to attend the *Mommies with Hope* group on an ongoing basis. Some women have attended since its beginnings in 2007. As a result, some of these women have become pregnant with a subsequent healthy child. Through this research, it is noted that women who are coping with this situation have unique needs, namely surrounding feelings of anxiety and worry over the unborn child. Although these feelings are absolutely validated and recognized among those at *Mommies with Hope*, I do believe it changes the dynamic of the group, particularly for those who may simultaneously be struggling with infertility, as described in greater detail in the findings in Chapter 5. Thus, an additional issue to address through future praxis and research revolves around these very issues.

### *Concluding Self-Reflection*

As I set out to complete this study, I did so with the experience of having lost my daughter, Chloe, due to a lethal prenatal diagnosis. It was a transforming time in my life, personally, professionally, and spiritually. I had grown a great deal and had learned so much. I was comfortable with where I was at in my own grief journey, three years later, I was ready to embark on a study of other women's experiences with loss, and more specifically, how they experienced support and validation for their losses through the *Mommies with Hope* support group.

What I did not expect was to experience this kind of loss again. Just as I received approval to begin collecting data for this study, I experienced an early miscarriage. Then, a few months later, as I was engulfed in data collection and analysis, I had a second trimester miscarriage. The initial plan to conduct a critical ethnography from the perspective of a bereaved mother who had “been there” three years prior began to shift. I was in the midst of my own grief, yet again. I could not approach the interviews and see the data with the same eyes I had before the miscarriages. It was so fresh. The grief was real. These babies existed and lived inside of me, if only for a moment in time. I was confused and hurt, but now understood to an even greater extent the nature of the silence and disenfranchisement that surrounds perinatal loss, particularly in the case of miscarriage. Now I knew what it was like to be that *Mommy* who felt unsure about coming to a support group when so many others had losses that were much more significant than my own. After all, they had given birth to their babies and their babies may have even lived for a period of time. Not my babies. They were here then gone. The very thoughts and words that I had debunked as they came forth from other *Mommies’* mouths, devaluing their loss experience and the life of their children lost through miscarriage based on the messages they received from others, now freely flowed from my own mouth. In recognition, I was determined to run this race that was set before me, embracing the lives of each of my children, reaching forward to contribute to the body of knowledge on perinatal bereavement as a form of disenfranchised grief. Critical ethnography, now interwoven with elements of autoethnography, became the vehicle by which I would cross the finish line.

But the race is not over just yet. The work completed through this study will continue on through *Mommies with Hope* most certainly, and perhaps through other groups or

programs who aim to support women enduring perinatal loss. The women in this study so graciously allowed me to enter into their lives through this research, to parts that others may have never seen. In fact, they welcomed me in, viewing it as an opportunity to share about their children and honor them. I cannot help but do something to unleash the chains that bind so many women to a silent grief experience. Even I, as a facilitator of *Mommies with Hope* and a researcher so adeptly aware of the disenfranchisement of such grief experiences, was inclined to suffer in my own silence. It took a bold leap for me “to not be silenced” and it is my endeavor to break the silence that disenfranchises women all over. This study is just one small step toward that purpose, yet the ramifications will endure with action. Such labor will not be in vain and these babies’ lives will be honored and their legacies will live on as the work I do continues to reach another grieving mommy, if even one woman at a time.

## APPENDIX A. FAITH STATEMENT

*Faith Statement*

***Called to reach grieving women for Christ,  
providing comfort and encouragement  
rooted in Scripture.***

**Praise be to the God and Father of our Lord Jesus Christ, the Father of compassion and the God of all comfort, who comforts us in all our troubles, so that we can comfort those in any trouble with the comfort we ourselves have received from God.**

2 Corinthians 1:3-4

**Our Beliefs...****The Bible**

We believe that the Bible is the inerrant, divinely inspired, written word of God. The bible is the final authority and speaks Truth. It is a perfect treasure of divine instruction. It has God for its author, salvation for its end, and truth, without any mixture of error, for its matter. Therefore, all Scripture is totally true and trustworthy. We believe the 66 books of the Old Testament and the New Testament are God's complete and sufficient revelation and therefore carry God's authority for the total well-being of mankind. ***Exodus 24:4; Deuteronomy 4:1-2; 17:19; Joshua 8:34; Psalms 19:7-10; 119; 160; Isaiah 34:16; 40:8; Jeremiah 15:16; 36:1-32; Matthew 5:17-18; 22:29; Luke 21:33; 24:44-46; John 5:39, 46-47, 10:35; 16:13-15; 17:17; Acts 2:16; 17:11; Romans 15:4; 16:25-26; 2 Timothy 3:15-17; Hebrews 1:1-2; 4:12; 1 Peter 1:25; 2 Peter 1:19-21.***

**God**

There is one and only one living and true God. God is all powerful and all knowing; and His perfect knowledge extends to all things, past, present, and future, including the future



decisions of His free creatures. We believe that the Godhead eternally exists in three persons: the Father, the Son and the Holy Spirit. These three are one God, having precisely the same nature, attributes and perfections, and are worthy of precisely the same honor, confidence, and obedience. *John 17:3; Mark 12:29; John 1:1-4; Matthew 28:19,0; Acts 4:3,4; Revelation 4:11; Hebrews 1:3; Acts 17:28; Deuteronomy 32:4; Psalm 9:8*

### **God the Father**

God is Father in truth to those who become children of God through faith in Jesus Christ. He is fatherly in His attitude toward all men. He created all things and upholds all things by the Word of His power. In Him we live and move and have our being. He is a God of truth and without iniquity, He is just and right, and He shall judge the world. *Deuteronomy 6:4; 32:4, 6; Psalm 9:8; Genesis 1:1; 2:7; Exodus 3:14; 6:2-3; 15:11; 20:1; Leviticus 22:2; 1 Chronicles 29:10; Psalm 19:1-3; Isaiah 43:3,15; 64:8; Jeremiah 10:10; 17:13; Mark 1:9-11; 12:29; John 1:1-4; 4:24; 5:26; 14:6-13; 17:1-8; Matthew 28:19; 6:9; 7:11; 23:9; Acts 1:7; 4:3,4; Revelation 4:11; Hebrews 1:3; 11:6; 12:9; Acts 17:28; Romans 8:14-15; 1 Corinthians 8:6; Galatians 4:6; Ephesians 4:6; Colossians 1:15; 1 Timothy 1:17; 1 Peter 1:17; 1 John 5:7.*

### **God the Son**

We believe that Jesus is God's only Son, who was conceived by the Holy Spirit and born of a virgin mother, Mary. We believe Him to be true God and true man, sinless and perfect and Savior of the world. He honored the divine law by His personal obedience, and in His substitutionary death on the cross He made provision for the redemption of men from sin. *Genesis 18:1; Psalms 2:7; 110:1; Isaiah 7:14; 53; Matthew 1:18-23; 3:17; 8:29; 11:27; 14:33; 16:16,27; 17:5; 27; 28:1-6,19; Mark 1:1; 3:11; Luke 1:35; 4:41; 22:70; 24:46; John 1:1-18,29; 10:30,38; 11:25-27; 12:44-50; 14:7-11; 16:15-16,28; 17:1-5, 21-22; 20:1-20,28; Acts 1:9; 2:22-24; 7:55-56; 9:4-5,20; Romans 1:3-4; 3:23-26; 5:6-21; 8:1-3,34; 10:4; 1 Corinthians 1:30; 2:2; 8:6; 15:1-8,24-28; 2 Corinthians 5:19-21; 8:9; Galatians 4:4-5; Ephesians 1:20; 3:11; 4:7-10; Philippians 2:5-11; Colossians 1:13-22; 2:9; 1 Thessalonians 4:14-18; 1 Timothy 2:5-6; 3:16; Titus 2:13-14; Hebrews 1:1-3; 4:14-15; 7:14-28; 9:12-15,24-28; 12:2; 13:8; 1 Peter 2:21-25; 3:22; 1 John 1:7-9; 3:2; 4:14-15; 5:9; 2 John 7-9; Revelation 1:13-16; 5:9-14; 12:10-11; 13:8; 19:16.*

### **The Holy Spirit**

We believe the Holy Spirit is fully God, equal with God the Father and God the Son and of the same nature. We believe that the ministry of the Holy Spirit is to glorify the Lord Jesus Christ. The Holy Spirit regenerates the sinner upon belief in Christ, baptizing the believer into one body of which Christ is the head. The Holy Spirit

indwells, seals, guides, instructs, fills, comforts and empowers the believer for godly living. The Holy Spirit convicts the world of sin, of God's righteousness and of coming judgment and He bears witness to the truth of the Gospel in preaching and testimony. ***John 16:8-14; Mark 13:11; John 14:26; Romans 5:5; I Corinthians 3:16***

### **Salvation**

We believe that salvation comes through belief in Jesus Christ as Lord and Savior. Salvation is a free gift, offered by God because of His grace. Jesus lived a perfect, sinless life on earth and eventually died a sacrificial death on the cross to pay the penalty for our sins. The only way to heaven is through faith and belief in Jesus Christ for full assurance of salvation from sin and death. We believe that salvation is granted at the moment one accepts Jesus as their personal Savior and Lord of their life, whereby they are born again. This is done by acknowledging oneself as a sinner and the need for a Savior, recognizing Jesus' righteousness and His death on the cross as payment for sin, and believing that He rose from the dead, conquering sin and death once and for all. One must ask Jesus to save them from their sin and repent, in light of His death, burial, and resurrection. ***2 Corinthians 5:21; Ephesians 1:4; John 3; Romans 8:37-39; 1 Corinthians 12:13; Romans 10:9-10; Hebrews 10***

### **Eternal State of Babies Upon Physical Death**


We believe that all babies, upon death, enter directly into God's presence in heaven. Babies are offered the free gift of salvation because of God's grace. According to the bible, those who reject God and do not accept Jesus as their personal savior go to hell. Because babies are not able to make such a choice, they are automatically granted eternal life in heaven through God's grace. Scripture reminds us of God's love for children and their innocence throughout, and the New Testament illustrates stories of Jesus' love and regard for children as well. ***Psalms 139; Psalm 22:9-10; Jeremiah 1:4-5; Luke 1:15-16; Galatians 1:15-16; Jonah 4:11; Jeremiah 19:4-7; Ezekiel 18:20; Job 3:11-19; Matthew 18:2-6; Matthew 19:14; John 8:21-24***

***Portions have been taken from the following Church's Statements of Faith:***

Lakeside Fellowship  
www.lakesidefellowship.com

First Family Church  
www.firstfamilyministries.com

## APPENDIX B. INSTITUTIONAL REVIEW BOARD (IRB) APPROVAL

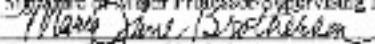
	Revised Date: _____	IRB ID: _____
	Approval Date: _____	Length of Approval: _____
	Approval Expiration Date: _____	PULL Committee Review: _____
	IRBMP1 per 45 CFR 46.101(b): _____ Date: _____	Minimal Risk: _____
	EXPEDITED per 45 CFR 46.110(b): _____	More than Minimal Risk: _____
	Category: _____, Letter: _____	Project Closed Date: _____

## ISU NEW HUMAN SUBJECTS REVIEW FORM

## SECTION I: GENERAL INFORMATION

Principal Investigator (PI): Teske R. Drake		Phone: 515-232-2789	Fax: _____
Degree: B.A., M.S.		Correspondence Address: 223 Ashton St., Gilbert, LA 50105	
Department: Human Development and Family Studies		Email Address: tdrake@iastate.edu	
Campus/Institute: NA		College: Human Sciences	
PI Level: <input type="checkbox"/> Faculty <input type="checkbox"/> Staff <input type="checkbox"/> Postdoctoral <input checked="" type="checkbox"/> Graduate Student <input type="checkbox"/> Undergraduate Student			
Alternate Contact Person: Mary Jane Brotherton, PhD		Email Address: mjbrotche@iastate.edu	
Correspondence Address: 51A Leaton		Phone: 294-3677	
Title of Project: "The God of all comfort": How Memories with Hope experience support through a biblically-based perinatal loss support group			
Project Period (Include Start and End Date): [month/day] [6/1/02] to [month/day] [6/30/10]			

## FOR STUDENT PROJECTS

Name of Major Professor/Supervising Faculty:		Signature of Major Professor/Supervising Faculty:	
Dr. Mary Jane Brotherton			
Phone: 294-3677		Campus Address: 51A Leaton	
Department: Human Development and Family Studies		Email Address: mjbrotche@iastate.edu	
Type of Project: (check all that apply)			
<input checked="" type="checkbox"/> Research <input type="checkbox"/> Thesis <input checked="" type="checkbox"/> Dissertation <input type="checkbox"/> Class project <input type="checkbox"/> Independent Study (490, 590, Honors project) <input type="checkbox"/> Other: Please specify: _____			

## KEY PERSONNEL

List all members and relevant experience of the project personnel. This information is intended to inform the committee of the training and background related to the specific procedures that each person will perform on the project.

NAME & DEGREE(S)	SPECIFIC DUTIES ON PROJECT	TRAINING & EXPERIENCE RELATED TO PROCEDURES PERFORMED, DATE OF TRAINING
Teske R. Drake, B.A., M.S.	Principal Investigator I will conduct all individual interviews, transcribe interviews, collect field notes, facilitate a focus group, serve as a participant observer, and conduct data analysis/interpretation and write-up.	IRB Online Training (Spring 09) Currently enrolled in a Writing Qualitative Inquiry class (ResEv 515-2), recently completed ResEv 580 (an advanced qualitative course on anti-oppressive methodologies), completed a qualitative thesis, and have taken the intro and advanced qualitative methods courses in HDPS
Mary Jane Brotherton, Ph.D.	Major Professor overseeing the research project, available for	IRB Online Training (10/02); Over 20 years of experience in

## APPENDIX C: INFORMED CONSENT DOCUMENT

### **Mommies with Hope Participants**

**Title of Study:** “The God of all comfort”: How *Mommies with Hope* experience support through a biblically-based perinatal loss support group.

**Investigators:** Teske Drake  
Mary Jane Brotherson

This is a research study. Please take your time in deciding if you would like to participate. Please feel free to ask questions at any time.

### **INTRODUCTION**

The purpose of this study is to understand the how women experience perinatal loss support through participation through the Mommies with Hope support group. You are being invited to participate in this study because you have experienced perinatal loss and attend the Mommies with Hope support group.

### **DESCRIPTION OF PROCEDURES**

If you agree to participate in this study, your participation will last up until January of 2010, or until you stop coming to Mommies with Hope. Your participation in this study will involve one to two interviews, lasting approximately 60 minutes each, regarding your experience with receiving support through Mommies with Hope. All interviews will be audio recorded and transcribed for data analysis. Recordings will be kept for five years and then erased. You may refrain from answering any interview questions that you do not feel comfortable with and can withdraw from the study at any time. In addition, it is expected that you may or may not have other forms of casual contact with the researcher, particularly by attending the Mommies with Hope support group monthly meetings and/or social events, and those interactions and conversations may be included in the data collection for this study as a form of participant observation. Upon completion of all interviews, you will then be asked to participate in a focus group discussion with the other participants in this study, aiming to gather information that will be instrumental in improving upon the current delivery of bereavement support through Mommies with Hope. You may choose to participate or not participate in any of the above-mentioned procedures.

### **RISKS**

While participating in this study you may experience the following risks: Emotional Risk. Due to the sensitive nature of the topics that will be discussed throughout the interview and observation process, you may be at an emotional risk.

**BENEFITS**

If you decide to participate in this study there may be no direct benefit to you, although talking about your perinatal loss and support experience may prove to be therapeutic. It is hoped that the information gained in this study will directly benefit the women who attend the Mommies with Hope support group, providing evaluative feedback and information that will assist facilitators of this group in providing continued bereavement support, as well as providing information on how to enhance the delivery of perinatal loss support, in accord with what mothers report helps and/or hinders their support experience.

**COSTS AND COMPENSATION**

You will not have any costs from participating in this study. You will not be compensated for your participation in this study.

**PARTICIPANT RIGHTS**

Your participation in this study is completely voluntary and you may refuse to participate or leave the study at any time. If you decide to not participate in the study or leave the study early, it will not result in any penalty or loss of benefits to which you are otherwise entitled, including continued support from the Mommies with Hope support group. Participating in this study may be terminated if I feel that you are at an emotional risk in which I am unable to adequately and effectively address your emotional needs. At this point, participation will be terminated and you will be referred to a trained mental health professional for assistance.

**CONFIDENTIALITY**

Records identifying participants will be kept confidential to the extent permitted by applicable laws and regulations and will not be made publicly available. However, federal government regulatory agencies the Institutional Review Board (a committee that reviews and approves human subject research studies) may inspect and/or copy your records for quality assurance and data analysis. These records may contain private information. To ensure confidentiality to the extent permitted by law, the following measures will be taken. Participants will be assigned a pseudonym, which will be used on all documents and data. The principal investigator will have sole access to all records from this study, which will be kept in password protected computer files. All hard copies of documents will be stored in a locked filing cabinet. The audiotapes of the interviews will be kept on file for five years and will then be erased. If the results are published, your identity will remain confidential.

**QUESTIONS OR PROBLEMS**

You are encouraged to ask questions at any time during this study.

- For further information about the study contact Teske Drake: (515)294-9578 or Mary Jane Brotherson: (515)294-3667

- If you have any questions about the rights of research subjects or research-related injury, please contact the IRB Administrator, (515) 294-4566, [jcs1959@iastate.edu](mailto:jcs1959@iastate.edu), or Diane Ament, Director, Office of Research Assurances (515) 294-3115, [dament@iastate.edu](mailto:dament@iastate.edu).

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### **PARTICIPANT SIGNATURE**

Your signature indicates that you voluntarily agree to participate in this study, that the study has been explained to you, that you have been given the time to read the document and that your questions have been satisfactorily answered. You will receive a copy of the written informed consent prior to your participation in the study.

Participant's Name (printed) \_\_\_\_\_

\_\_\_\_\_  
(Participant's Signature)

\_\_\_\_\_  
(Date)

### **INVESTIGATOR STATEMENT**

I certify that the participant has been given adequate time to read and learn about the study and all of their questions have been answered. It is my opinion that the participant understands the purpose, risks, benefits and the procedures that will be followed in this study and has voluntarily agreed to participate.

\_\_\_\_\_  
(Signature of Person Obtaining  
Informed Consent)

\_\_\_\_\_  
(Date)

## APPENDIX D. OBSERVATION/INTERVIEW SUMMARY SHEET

**“The God of all comfort”: How *Mommies with Hope* experience support through a biblically-based perinatal loss support group.**

Interviewer/Participant Observer: \_\_\_\_\_

Observation/Interview Date/Location: \_\_\_\_\_

Participant(s): \_\_\_\_\_

1. Briefly describe/reflect on the person(s) involved.
  
2. What were the main impressions or issues that struck you in this contact?
  
3. Summarize the information/ideas you got (or did not get) on target research questions:

Research Question	Information
How do mothers experience support for and recognition of their perinatal loss experience by participating in the Mommies with Hope support group?	
How does the group help or hinder bereaved mothers' support experiences?	
How does participation in the group validate mothers' experiences with perinatal loss?	

4. How is support provided? (What are moms saying about the group that is supportive?)
  
5. Describe anything else that struck you as salient, interesting, or important in this contact?
  
6. Are there any areas needing clarification/further exploration in subsequent observations/interviews?

## APPENDIX E. INTERVIEW PROTOCOL

**“The God of all comfort”: How *Mommies with Hope* experience support through a biblically-based perinatal loss support group.**

- Tell me about the loss of your pregnancy/baby (use child’s name)
  - Did you have a funeral or other type of memorial service? What are your thoughts about that?
- What sources of support did you have during this time?
  - Who or what was most/least helpful to you?
- What has the grief process been like for you?
  - Who or what has been your greatest source of support?
  - Who or what has been most/least helpful as you experience your grief?
  - What advice would you give to another bereaved mother seeking support?
  - Can you think of times when you have felt unsupported in your loss?
  - Tell me about a time when you have felt as though your loss has gone unrecognized.
- When and how did you become involved with Mommies with Hope? What keeps you coming back? Can you describe a typical support group meeting from your perspective? How is Mommies with Hope different than other forms of support you’ve experienced?
- If someone were to ask you to tell them about Mommies with Hope, what would you say?
- How has your participation in Mommies with Hope validated your loss experience?
- What has been most/least helpful about this group?
  - Name specific activities, events, etc.
- How has the group served as a source of support? (specific ways – meetings, prayers, online resources, social events, friendship, etc...) Can you give an example of a time when you felt supported by the group?

If you could change anything or things about the support you receive(d) (or didn’t receive) from Mommies with Hope, what would they be?



## APPENDIX F: SECOND FOCUS GROUP SOLICITATION

Hello Ladies,

I am emailing a select few of you regarding Mommies with Hope this Thursday, wondering if you were planning to come and if so, if you would be able to come 30 minutes prior to our regular meeting time? The reason I ask is because, as some of you know, I am doing my dissertation research on how women experience support for their losses through participating in Mommies with Hope. I am thankful to many of you for already being a part of this research.

I am nearly finished with my project, but a couple of weeks ago, I had the misfortune of losing some of my data due to a technological glitch in my recording device, which in turn deleted the previous focus group that I had conducted that some of you were a part of. I was hoping to get a few of you together for 60 minutes before the regular meeting to discuss some very focused questions about how support is experienced. I would use an audio voice recorder to record our conversation. Here are the specific questions I plan to ask:

- 1) What is the main reason you come to Mommies with Hope?
- 2) How has the group been a source of support for you?
- 3) What role does spirituality play in your experience of support?
- 4) Do you feel Mommies with Hope is a "safe place" to talk about/share your loss experience? Explain.

Please do not feel obligated to come to this "mini focus group" if you are not comfortable. It is completely voluntary and you are more than welcome to just come to the meeting if you were already planning on it! For those of you who were not planning to come this month, but would still like to contribute your feedback to the questions posed above, please feel free to email me any responses/feedback. This is also an option for those of you who do plan to come. I am very appreciative for each of your time and feedback to help make this group a great source of support for women who experience loss!

Thank You,  
Teske

## APPENDIX G. FOCUS GROUP PROTOCOL

**“The God of all comfort”: How *Mommies with Hope* experience support through a biblically-based perinatal loss support group.**

- Discuss with each other how the group has been a source of support for you.
  
- Discuss with each other how the group has validated your loss experience.
  
- Of the current ways in which we provide support (face-to-face meetings, prayer, discussion/sharing, web-based support, socials, etc.), which would you say is most helpful to you and why? Discuss with each other about your choice.
  
- Where else do you or have you receive(d) support for your loss?
  - Compared to other sources of support, what makes this group similar and/or different? Based on these things, what keeps you coming back?
  
- In your opinion, what would be most helpful in terms of receiving support from this group (can be things we already do, things you would like to see incorporated, etc.)?
  
- What ideas for improvement do you have for this group?

## APPENDIX H. DATA ANALYSIS EXAMPLES

### Progression of Emergent Themes

EMERGENT THEMES: February 14, 2010

- Safe Place to talk/Safe Haven → Validation
  - Significance of the “Word”
  - Circulation of Support
  - Support Extends Beyond the Group
    - Web-based
    - Contact outside of meetings
    - Other circles
    - Friendships that are formed
  - MWH as a way to minister to others
  - Silenced in their grief
  - Evangelical Christianity perspectives versus Roman Catholicism perspectives on the role of the bible
- 
- Areas of Positive Reframing
    - Comparing Losses
    - Issue Focused
    - Doctrinal Differences

## EMERGENT THEMES: March 8, 2010

### Overarching/Encompassing Themes:

- A Safe Haven
- Linked by Our Loss
- Silence is Broken

### Experience of Support Themes:

- Minister to Others
- Child's Life is Validated
- Receive Comfort
- Friendship
- Spiritual Growth
- Ongoing

### Outside of the Group:

- Support extends beyond the group
- "Comforting the comforter"
- "unable" to talk about their child/silenced

## IN/OUT OF THE GROUP – EMERGENT THEMES AND EXTERNAL INFLUENCES

IN THE GROUP	OUTSIDE OF THE GROUP
Child's life is validated	Child's life often goes unrecognized
Shared Experience	Isolated
Ongoing Support	Move on, "try again"
Silence is broken	Silenced
Receive Comfort	"Comfort the comforter"

## FINAL LIST OF THEMES

### Encompassing Themes:

- Our Hope Stories: Linked by Loss
- Silence is Broken
- *Mommies with Hope: A Safe Haven*

### Sub-Themes:

- Receive Comfort over Time
- Experience Validation
- Build Friendship
- Foster Christianity
- Able to Help Others

# coding key

## FINAL LIST OF THEMES - March 20, 2010

### Overarching/Encompassing Themes:

- A Safe Haven
- Linked by Our Lives
- Silence is Broken

over & over we see women coming who are just waiting to share - ex: subsequent losses, new pregnancies, etc. - the expected

Comforting the comforter → results in silence  
 (would it all together?)

### Experience of Support Themes:

Able to help

- ~~Comforter to Others~~

- Experience is Validated
- Child's Life is Validated

- Receive Comfort

- Build Friendship

Foster Spiritual Growth

- ~~Engage~~ Receive Support over Time

riches/lack of acknowledgment by others → experience validation in the group

## Sample Observation/Interview Summary Sheets

180-000-001	01-000
Approval Date:	21 Aug 2009
Approval Date:	19 Nov 2009
Approval:	Dr

## Observation/Interview Summary Sheet

"The God of all comfort": How *Mommies with Hope* experience support through a biblically-based perinatal loss support group.

Interviewer/Participant Observer: T. P. S. K.  
 Observation/Interview Date/Location: Sept. 17, 2009 Mtg. Lakeside Bldg. Park City  
 Participant(s): MWH Group

1. Briefly describe/reflect on the person(s) involved: 5 women present (including me) 2-3 regular attendees rest newcomers; equal sharing/listening for the most part; only 1 other was led to pray out loud
2. What were the main impressions or issues that struck you in this contact? lots of prayer - 2 major issues faced by women who've struggled: infertility

3. Summarize the information/ideas you got (or did not get) on target research questions:

Research Question	Information
How do mothers experience support through participation in the <i>Mommies with Hope</i> Support group?	<u>sharing, asking for prayer, praying at the mtgs, talking/listening to each other</u>
How does the group help or hinder bereaved mothers' support experiences?	<u>help - prayer, listening, safe place to share/talk, confidentiality</u> <u>hinder - I wonder about this aspect of those who are expecting again &amp; in the future</u>
How does participation in the group validate mothers' experiences with perinatal loss?	<u>open forum to talk about it - not really able to talk about it in other places/settings (my interpretation)</u>

4. How is support provided? (What are moms saying about the group that is supportive?)  
prayer, asking questions of each mom, listening

5. Describe anything else that struck you as salient, interesting, or important in this contact?

- 2 women stayed after to talk w/ me - informal, casual - mostly pertaining to the "next child" they are each expecting; one mom opened up about infertility struggles

6. Are there any needs needing clarification/further exploration in subsequent observation/interviews?  
validation piece of it

shared news about an Africa group possibly starting up - moms were invited, cooperative, etc.

Form 1	01/01/08
Revised Date:	21 April 2008
Revision Date:	19 April 2008
Initials:	

### Observation/Interview Summary Sheet

"The God of all comfort": How *Mourners with Hope* experience support through a biblically-based perinatal loss support group.

Interview/Participant Observer: Teske Drake  
 Observation/Interview Date/Location: WPA, Wisc. - Dec. 21<sup>st</sup> 7pm E-Free Church, DC.  
 Participant(s): small group tonight (me + 4 others)

1. Briefly describe/reflect on the person(s) involved  
 range of losses, some quite recent - 2 who were quite fearful; one very reliant on "God's love"  
 2 who lost twins
2. What were the main impressions or issues that struck you in this contact?  
 Christmas "Home" - Jesus came as a baby - God's love for us that He sent His only Son (John 3:16)  
 One woman felt that her loss was punishment
3. Summarize the information/ideas you got (or did not get) on target research questions:

Research Question	Information
How do mothers experience support through participation in the <i>Mourners with Hope</i> Support group?	safe place, shared understanding L this mom talked about prayer her own mother's / her friends look of understanding Scriptures to address loss as punishment / God's love
How does the group help or hinder bereaved mothers' support experiences?	Prayer, offer resources, outside of the group emails / correspondence etc.
How does participation in the group validate mothers' experiences with perinatal loss?	Safe place we understand when others (who haven't been thru it) don't

others  
"leader"

4. How is support provided? (What are moms saying about the group that is supportive?)  
 prayer, resources (books, devotionals → shared via email), blog posts  
 open floor to talk  
 L one mom borrowed  
 one mom emailed for titles
5. Describe anything else that struck you as salient, interesting, or important in this contact?  
 one mom's search for God - wanting to understand the Gospel even when a friend totally disagreed with her - follow up necessary as form of evangelism (in line of group's mission)
6. Are there any areas needing clarification/further exploration in subsequent observations/interviews?

Safe place aspect  
 & what keeps them coming back?



SUBJECT:	15-100
ANALYST:	2-1000000
DATE:	01/01/2011
BY:	11

### Observation/Interview Summary Sheet

"The God of all comfort": How *Moments with Hope* experience support through a biblically-based perinatal loss support group.

Investigator/Participant Observer: Tasha  
 Observation/Interview Date/Location: Thurs., Nov. 19th 7pm, Lakeside Bldg - HHS Int'l  
 Participant(s): MWH Group - 10 other women present; 2 new women

1. Briefly describe/reflect on the person(s) involved.

Range of losses ~ infertility, miscarriage, stillbirth, prematurity, twin loss, relinquish for adoption, term due to lethal diagnosis, perinatal hospice

2. What were the main impressions or issues that struck you in this context?

several spoke up, participated more fully than in past; lots of discussion on adoption

3. Summarize the information/ideas you got (or did not get) on target research questions:

Research Question	Information
How do mothers experience support through participation in the <i>Moments with Hope</i> Support group?	prayer - beginning, end; spontaneously based on need that lady show in making connections w/ similar experiences "safe place" to talk
How does the group help or hinder bereaved mothers' support experiences?	encourages participation ~ open up for prayer, discussion of issues specific to women, offers time for fellowship
How does participation in the group validate mothers' experiences with perinatal loss?	"safe place" to talk; not alone ex: one woman went to a coworker first b/c she knew she'd "been there" ~ someone who understands

not everyone comfortable

4. How is support provided? (What are turns saying about the group that is supportive?)

connections w/ similar experiences ~ thankful enjoy time together  
 feel welcomed, not judged follow-up  
 glad they came

5. Describe anything else that struck you as salient, interesting, or important in this context?

Lots of adoption talk; infertility struggles  
 subsequent pregnancy anxiety, fear

6. Are there any areas needing clarification/further exploration in subsequent observations/interviews?

spirituality ~ what role in individuals' experiences - may be a question for interviews, not the group

## Sample of Coded Transcript Excerpt

who had carried a baby well into her second trimester and had a still birth. So, you know, and I've always felt like I've always been burdened and just had a big place in my heart for women who have either gone through this or who are struggling with fertility issues. And so I would say that first night that I went I was not going thinking, o I need encouragement I need support. And it wasn't until, and even when people started going around and introducing themselves and introducing you know just kind of telling everybody about what they've gone through I even at that point felt kind of like I don't really feel like I need to say anything about me. And then when it came to me, it was just like my emotions just took over.

T: And would you say your view or your attitude about your own sense of support, like you know you mentioned coming more so to support a friend, and but you've come back and you've participated in social events and things like that. I guess, what keeps you doing those things.

N: Now I feel like maybe the Lord wants to use me to help support other women who have gone through very similar circumstances as I've gone through. And I feel like since I've come there have been women with that, those same circumstances. And so I think even that the Lord just may be using me in that way.

T: Well and just from my, you know I've said this before, in the group and outside the group. You know it's not like I'm just the leader of this group, because I received just as much support and encouragement and everything else along the way. And it's just interesting that you say that because when we had this last miscarriage and Pastor Dave wasn't in his office you were the first person that I called. And just knowing that I could call, and you'd be there and in your pajamas and still letting me come and while in your doorstep. And I think that's so true just from my perspective being on the receiving end of your willingness to be used, so that's been a blessing for me.

N: Yeah, Thanks.

T: Yeah. But that's kind of, I felt the same way after the first miscarriage because I knew what it was like to have a baby closer to full term who lived for a little bit and see, touch, hold, and all of

Help Others

didn't think she needed support

Help Others

purpose/meaning;  
spirituality

my story of feeling supported by NH

pastor Dave

that. And I didn't understand some of those things that you and others were saying about early miscarriage about feeling like I don't know if I, if my loss is as important. Or no, you know I'm grieving as much or things like that and I'm like what are you talking about. You know, you didn't understand it and then when I had an early miscarriage it was a different grief but it hurt so much. And I just remember being able to relate to those women in particular. So that's another thing that was kind of alerted to in your interview and also with other women that I've talked to is continually coming back to Monnics with Hope offers opportunity to minister to others. And so is that kind of what you're saying?

N: Yeah. Yeah, I think that after that initial encouragement and support that I received and I think just being able to get that expression out and have my feelings validated. You yet know that now maybe the group can use me to help encourage. And I feel like to because so much time have gone by since my miscarriage has happened and that it's just <sup>not</sup> as fresh.

T: Fresh?

N: Right it's not as fresh but I think that, that initial time when I came to that first meeting I hadn't talked about it for so long. I hadn't brought it up and I think bringing it up again and talking about it just like made it all kind of resurface. But I think since that time it's still very sad and it's not that I don't think about it especially because at Christmas this year I think the baby would have been five. And we were due on Christmas day. And so there's just certain milestones I think that I'll never forget, that will bring that sadness and that emotion to the surface that I think for the most part I want to be able to be used as an encouragement for others.

T: That's awesome. It's a hard thing to have to be in that position, you know but when I went and spoke to the class up at North Western I have more freedom there, they're a Christian college. Somebody asked a question and my response was how you know we can use the bad things that happen in our lives as a platform for ministry. You know that give us the experiences and what are we going to do with them and it sounds like you want to be able to help people who have gone through something similar. You

*Validation  
and helping others*

*Just  
quite*

*Helping others*

AS1

3

happening in their lives currently, or if there's somebody new, being able to share their past experience again to kind of open up doorways that people so people connect with those who have gone through similar experiences as themselves. Someone will usually share some Scripture. A lot of times Teske or Lindsay, and then other people are sometimes led to maybe a passage they've read or connection that they find, and then we usually close with prayer and then we stick around and chat some more...

T: Sometimes for quite a while

A: For quite a while sometimes! (both laughing)

T: But that's good. Well you mention that you have been in, you have had other types of support, even other types of formal support with RTS or Perinatal Hospice, or things like that. How would you... would you say Mommies with Hope is different than that or not, or I guess how would that compare?

A: I would say Mommies with Hope is different because it's just the women. The women definitely connect and relate differently to the loss than men. Not bad difference, but different. It's a different experience for dads than it is for moms. So, it's definitely more focused on the mother experience.

T: Well and I think sometimes there are things that we share that we wouldn't necessarily share in front of our husbands. Sometimes our issue is our husband.

A: Sometimes. (both laughing)

T: Not understanding or not, you know.

A: Not relating. — spouses; inconstant grief

T: Yeah, and so that's a big one too that I see.

A: I think that's the biggest one. And being biblically-based. That's huge. Because like RTS was not at all biblically-based. It was there, it was basically psychology. I mean, it was her background and you know that's great, but it's not...

T: But for you and kind of where you're at, it was, you needed more of the Word would you say, or...?

women-centered

shared

supportive

significance of the word

but because I said some things

AS1

6

A: Yeah. More World, more. I mean, when God's involved it's just, you know it's not for nothing. You know it's not just to cause you pain and grief and you know there's something else there. When God's not involved, it's just, I would assume... I didn't go through it without God, but I would assume it'd feel like the world's out to get you, or like the world's falling apart.

God ~~gives~~ gives the child's life meaning/purpose

T: Right. And I think when you take God out of the equation like that, it almost takes away purpose and meaning for your child's life.

A: Yeah, it basically becomes meaningless.

T: And just how to cope with the feelings as opposed to seeing purpose and meaning behind it.

A: Mmmhmm.

T: That's interesting. I hadn't thought about that....How has your participation in Memories with Hope validated your loss experience?

A: How has MWH validated my loss? (not sure she understood this question)

T: Yeah, and you can and it doesn't have to be necessarily about Noah specifically, it can be about just the experience as a whole, or even some of the current struggles (infertility) that you might be facing.

A: I think it's, again it's that purpose - being able to share, being able to help, being able to relate to somebody else and somebody's who's maybe at an earlier stage of what you're going through, whether they're just finding out or just getting to that grief stage if there are actually like stages of going through it - um, it's a safe place to talk about it, because it's not like you can... I mean now that it's been two and a half years, I can't just bring it up or bring Noah up wherever I, I mean not everybody gets that. I think it even weirds, sometimes, some people out.

safety

silenced in her loss

T: Can you think of an example where maybe it has "weirded" somebody out?

A: Like if somebody's pregnant, and they knew we lost Noah, and they say something about being pregnant and then I say something about being pregnant, it's just kind of almost like a conversation stopper.

pull quotes

ASI

7

T: Really?

A: It's like a...

T: Like awkward moment?

A: Yeah. Depending on the person. Some people it doesn't bother, other people it's an awkward moment. Especially if I don't know them very well. They just know about it after the fact, like I had just met them in the past year or something, then it's just...

T: Like they weren't around when you were pregnant with Noah.

A: It's interesting. But at Mommies I can share the memories and share the stories and everybody wants to hear and everybody wants to share.

T: And ask.

A: And ask?

T: So, would you say there's, like do you feel sometimes like when you're in these situations around women who are pregnant or talking about childbirth or whatever that you have to kind of monitor what you say?

A: Depending on the situation (stated very matter of factly). And especially if there's people in the room who don't know about Noah and then I start bringing up being pregnant and they know I don't have any living kids, then it even brings up into another awkward like bridging that... cuz they're clued into the conversation or to me and then they'll ask and that can be awkward too. Not for me, for them (chuckling).

T: Right...that's what I was just about to ask you to follow up on like, um, I think a lot of times as bereaved mothers we are left consoling other people. Do you feel that way?

A: Mmmhmm. I do. Like when I tell somebody for the first time and they're like "oh, I'm so sorry." And I'm like "it's okay." Yeah, I mean. It's been a... you end up making them feel better for asking and bringing up something that's... well so then they're bringing up something horrible... to us it's like it's a good thing.

T: Yeah, it's like, oh I got to talk about him.

Safe Place!

comforting the comforter

↓  
consoling others

AS1

8

A: Mmmhmm. And that's usually what I say. Oh it's okay, I get to share now, or I love to talk about it. Like people comment about my pictures on my desk and I'll share. And they're like "oh I didn't mean to bring it up." "No it's okay, the pictures out so you can bring him up."

*silence is broken*

T: Yeah. That's awesome. Well I think, kinda going back to a safe place, people who haven't been through something like that don't realize that it's okay to bring up and that really, you know, that's a welcome conversation. You know like I could come up to you or vice versa or Nicole or somebody else and easily ask, how are you doing, how were the holidays for you, things like that knowing that that's maybe welcome, as opposed to someone who hasn't been there wouldn't dare ask.

A: Mmmhmm.

T: What would you say has been the most and/or the least helpful about the group?...And don't feel like you have to sugar coat anything (both laughing).

A: I'm not sugar coating anything! (both laughing)

T: I know you don't! (still laughing)

A: Um, most helpful is just being able to share and being able to talk and having that common bond and the hardest thing or the least helpful - I dunno. That's a hard one.

*silence is broken in the group - most helpful*

T: How would you say...what about the social aspect of the group, you know we've done things where we have our husbands come or even things just us ladies...has that part been helpful to you in terms of support or more of friendship or...?

A: Probably more friendship than support because when we're together with our husbands we really don't talk about, I mean, we know that it's the common thing that's brought us together, and we'll pray about it or have the cake and stuff at our last one, but it's not the purpose. The purpose is just to get together and socialize, which I think is good too. I think being able to develop those friendships makes the group stronger when we come back together to talk about our losses.

*Build Friendships  
social events*

T: Yeah, that's a good point. Because then it's like we at least are getting to get to know each other outside of the losses, you know

*pull quote*

*pull quote*

*pull quote*

### Sample Methodological Log Entries

February 5, 2010

#### *Another Loss*

My heart is still heavy with sorrow today, as I just received word of another dear friend who is experiencing a miscarriage. It came as a shock to me when I received a call from her husband, asking my “expertise” about the situation they found themselves in and what the ethical implications are of the choices they were faced with: 1) to let nature take its course, 2) take an oral medication to induce the process, or 3) to have a D & C. What a humbling thing to be chosen to be an “expert” on such a thing. It pains me that others have to endure this. And Susan was there last night, rallying around Amanda in her time of grief and sorrow. She was there to lift her up in prayer and support her, even in the midst of her silent grief – none of us knew. Others may have, but neither Amanda nor I did. Oh my heart aches for her in the most tender spot today. I don’t know what God is up to through all this that surrounds me lately. I don’t understand how He intends to use this in these women’s lives or my own, but I feel it is all for something.

March 29, 2010

This past weekend I was able to spend some quality time with Sarah, as we had lunch on Friday (with a group of ladies from church), met back up that evening for our church’s women’s conference/retreat, where we sat together, stayed in the same hotel room, and then sat together all day on Saturday. Interestingly, at the lunch on Friday, there were 9 women total. Of the nine women, 6 of the women had experienced loss (including me). Of those 6, 5 were active at some point in *Mommies with Hope*.

At the lunch and throughout the weekend there were various times when Sarah’s son came up as well as Chloe or my losses. We had fun memories and laughed together about some things, but we also teared up at times remembering our babies. As the weekend went on, it became more and more apparent that Sarah was really struggling with the current infertility she is facing. She made comments like, “how can you worry about something that you should be thankful you have” when thinking about a friend who is pregnant and does nothing but worry. I tried my best to empathize with her, but I have to admit that I don’t know what the infertility is like, and I am blessed to have 2 living children.

Toward the end of the conference during some designated quiet time, Sarah was quite tearful and bitter about the situation, seeing that so many women there had newborn babies with them or were pregnant. I turned to her and took her hands and just cried and prayed for her. It was a precious moment in my mind and was all I felt I could do to support her. Our Pastor’s wife was sitting at our table and she too came alongside Sarah and prayed with her after I did. It was a precious time for us. I felt a peace in doing so and I think Sarah did too.



March 21, 2010 Reflection – Observation/Member Check with Ann and Kate

I ended up having the chance to meet with Ann and Kate this evening. We were able to reconnect since neither of them have been coming to the meetings for the last few months. Based on our conversations, I know Ann was very sensitive to the other women considering the fact that she is pregnant and actually just recently gave birth to her healthy baby girl (3 weeks ago). Kate shared that she too is pregnant – 12 weeks along. It seems like the pregnancies impact their comfort level in the group, given their sensitivity to the other women, particularly those who are struggling with infertility.

When we met tonight we talked more about the loss experiences, including topics like: frustration with the cost of a D&C, the prevalence of loss, medical procedures, etc. Also, the women talked about their heart for other women who have gone through something similar. I shared with them some of my emerging themes and the “bio’s” I had written for each of them. They were both in agreement with what I had written and the discussion of the emergent themes spurred on discussion.

**Member Check Example: Analytic Notes & Participant Bio**

<i><b>RESEARCH QUESTIONS</b></i>	<i><b>NARRATIVE/INTERVIEW EXCERPTS</b></i>	<i><b>CRITICAL ETHNOGRAPHIC INTERPRETATION</b></i>	<i><b>EMERGENT THEMES</b></i>
<b>HOW DOES SHE EXPERIENCE SUPPORT THROUGH MWH?</b>	<p>T: Do you feel like there are other, like if you look at your life, your surroundings, the people you affiliate with, your friends, family, whatever...do you feel like there are other circles where that is accepted, those kinds of conversations or do you feel free to talk about those things or do you think that it's more exclusive to being in the Mommies with Hope setting?</p> <p>N: I do feel like it's more exclusive to being in the Mommies with Hope meetings and talking to those women about it. I honestly, to tell you the truth, I don't...I mean there are very few, I should say, times or opportunities where I would feel comfortable elsewhere to</p>	<p>Women who experience perinatal loss often feel as though they do not have permission to talk about their child or their loss experience with others. The Mommies with Hope group offers women the opportunity to openly share their feelings and experiences surrounding their perinatal loss experience. When I asked Ann about whether she feels as if there are other "circles" where such conversation is accepted, she responds by saying, "I do feel like it's more exclusive to being in the Mommies with Hope meetings and talking to those women about it...to tell you the truth...there are very few, I should say, times or opportunities where I would feel comfortable</p>	<b>SILENCE IS BROKEN IN THE GROUP</b>

	share that with a group of people.	elsewhere to share that with a group of people.”	
<b>HOW IS HER LOSS VALIDATED BY PARTICIPATION IN MWH?</b>	<p>“...the first time that I came to a Mommies group, I didn't necessarily think I was coming for myself you know I thought I was coming to support my close girlfriend who had, you know, what I felt like at the time, a greater loss than mine. Not because that's what I felt, but because that's what I feel the world leads us to believe, you know. That they put value and judgment on these babies lives, regardless of how short or long we carried them in our bodies. So I think that first night when I came, I mean I remember when everyone was going around in a circle introducing themselves and could, you know, share about their loss, I remember thinking I knew I was going to be emotional but I didn't want to be because I didn't want people to think "why in the world is she, you know, what has she, why is she getting so emotional, what does she think that she's</p>	<p>Ann initially came to the group to support a friend. She was bringing a friend who had experienced a loss later in her pregnancy (18 weeks) who had to physically deliver the baby and who had the opportunity to see, touch, hold her baby. Ann had been used to the messages she received from society that minimized her own miscarriage experience. She compared her loss to others and admitted that she felt that she did, in fact, devalue her own loss experience. Coming to the group, however, offered a sense of validation and recognition for what she had been through in her own loss experience.</p>	<p><b>EXPERIENCE VALIDATION</b></p> <p>Her loss was recognized as important, even when she was devaluing it herself</p>

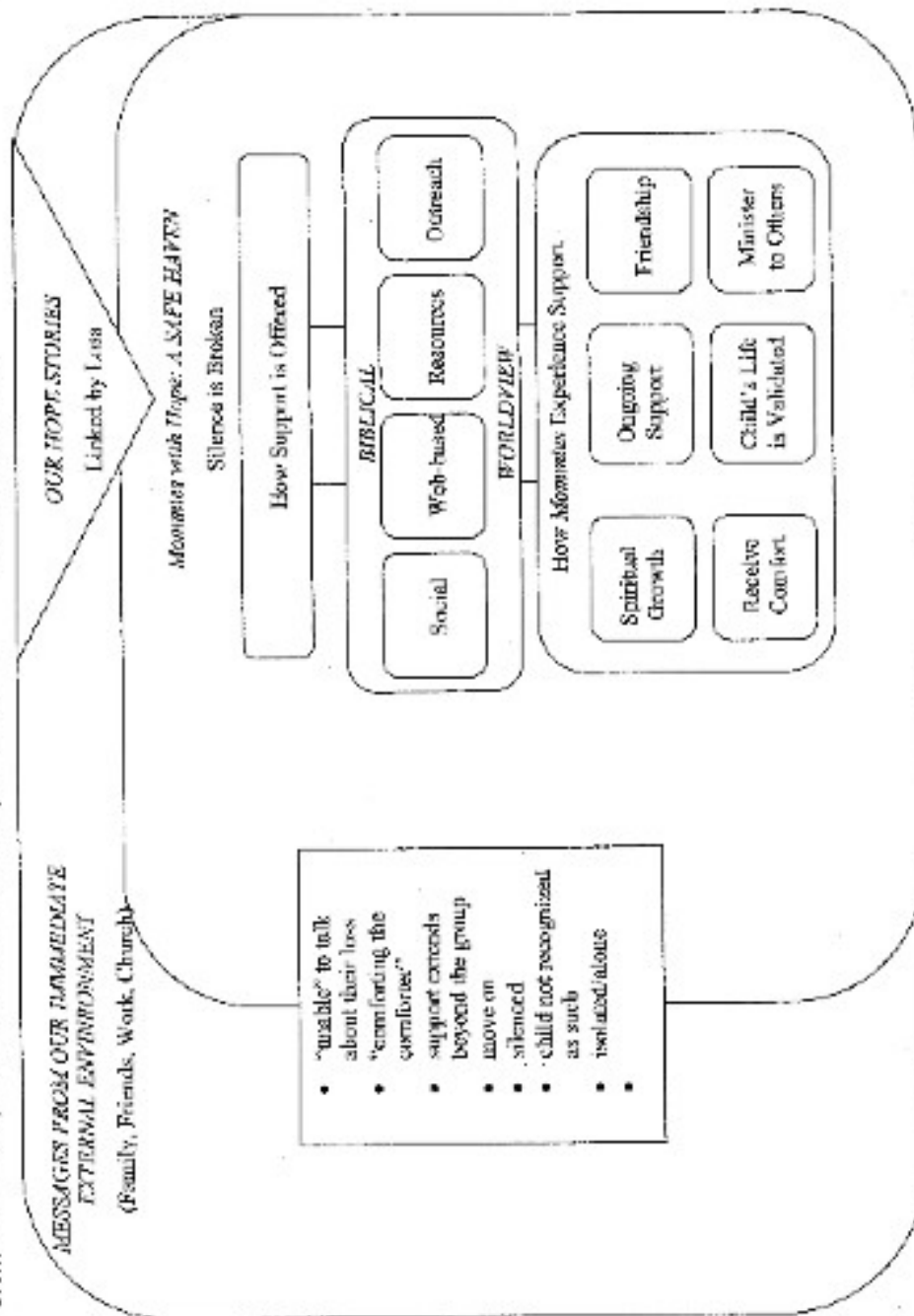
<p><b>HOW IS HER LOSS VALIDATED BY PARTICIPATION IN MWH? (cont'd)</b></p>	<p>gone through that's so difficult" you know which is obviously completely the opposite of what I experienced, but I think you keep your emotions and your feelings bottled up. They're tucked inside of you so much because of the response that you 9 times out of 10 more than likely receive from people when you share with them, you know."</p>	<p>Here, Ann is again talking about being "completely validated" by the group. She falls into comparing losses, again. I remind her that she had not had that opportunity to share with a group of women. In fact, it had been five years since Ann's loss, but this was the first source of formal support she had every had the opportunity to take advantage of. I had a</p>	<p><b>EXPERIENCE VALIDATION</b></p> <p><b>SILENCE IS BROKEN –</b></p> <p>she is able to talk about, even after five years since her loss</p>
	<p>T: How has your participation in Mommies with Hope validated your loss experience?</p> <p>N: Completely (accentuated) validated, which you know, I, I just remember that first night that we met and after I had shared, and had been bawling and to the point where I could hardly even finish my story, but and still just feeling like, almost kind of embarrassed like, I can't believe I just broke down like that, sharing my story when like Sarah and</p>		

	<p>Hannah and you know..</p> <p>T: But if you haven't had that opportunity...</p> <p>N: Right, right, but I remember you saying right after that had happened, you made some type of comment that just totally kind of made a calmness and made me feel at ease, and just kind of the way you said it too was just, like you weren't, I know you were speaking to me, but the way you worded it was like you were talking to the group and you just like made a comment like see how quick we are to put degrees of importance on each our losses, I don't remember exactly how you worded it, but just how they're all important on their own and there's not one that is more significant than another, you know, and I think that was just really when my heart really started to open you know and I was like this is good, this was good coming to do this you know and um, yeah...</p>	<p>conversation with her about this and she recalled that the hospital had given her “nothing” – she had no information or sources of support for her loss. So now, five years later, she was able to come to a group and share and experience validation from a group of ladies who had “been there”.</p>	<p>Her “ability” to talk about it makes MWH a</p> <p><b>SAFE PLACE</b></p>
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*Ann*

Ann is a 34-year-old mother to four girls. In 2004, she experienced a miscarriage just toward the end of her first trimester of pregnancy with her third child. She has since given birth to two healthy children. Ann realized that she was experiencing a miscarriage when she and her husband went to the doctor for a routine prenatal visit. The nurse was unable to locate the baby's heartbeat with the doplar, which then led to the medical staff performing an ultrasound. The baby had no heartbeat, which is the moment that Ann realized her baby had died. She went through a D&C surgical procedure (dilatation and curettage) the next day, as recommended by her doctor and found great comfort in her husband's support and prayers during that time. Ann first attended Mommies with Hope in the Spring of 2009, nearly five years after her loss. She initially came to bring and support a friend who had experienced, in her words, a "greater loss" than her own. However, she found herself receiving comfort and encouragement from the women when she shared her own story of loss by miscarriage, and has continued to find validation through Mommies with Hope. Ann really enjoys being able to come alongside other hurting women who have been through something similar and sees the group as a way to "minister" to them.

Ann and I met for the first time in winter of 2008/2009. The church she was attending had approached the church I attend about combining. In this process, our churches began to coordinate events and activities together, which is how we met. Ann learned of *Mommies with Hope* through other women in the church and shared with me about the loss she had experienced in 2005. Since meeting just over a year ago, Ann and I have become good friends through church and through *Mommies with Hope*.



## Progression of Visuals

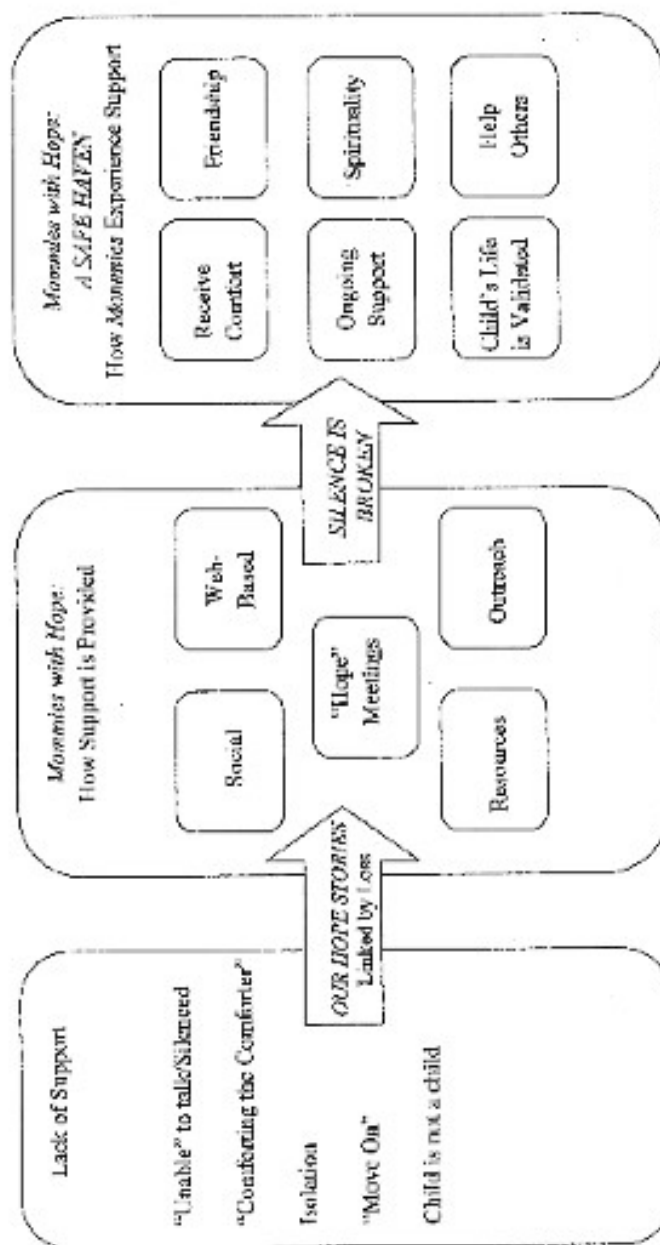
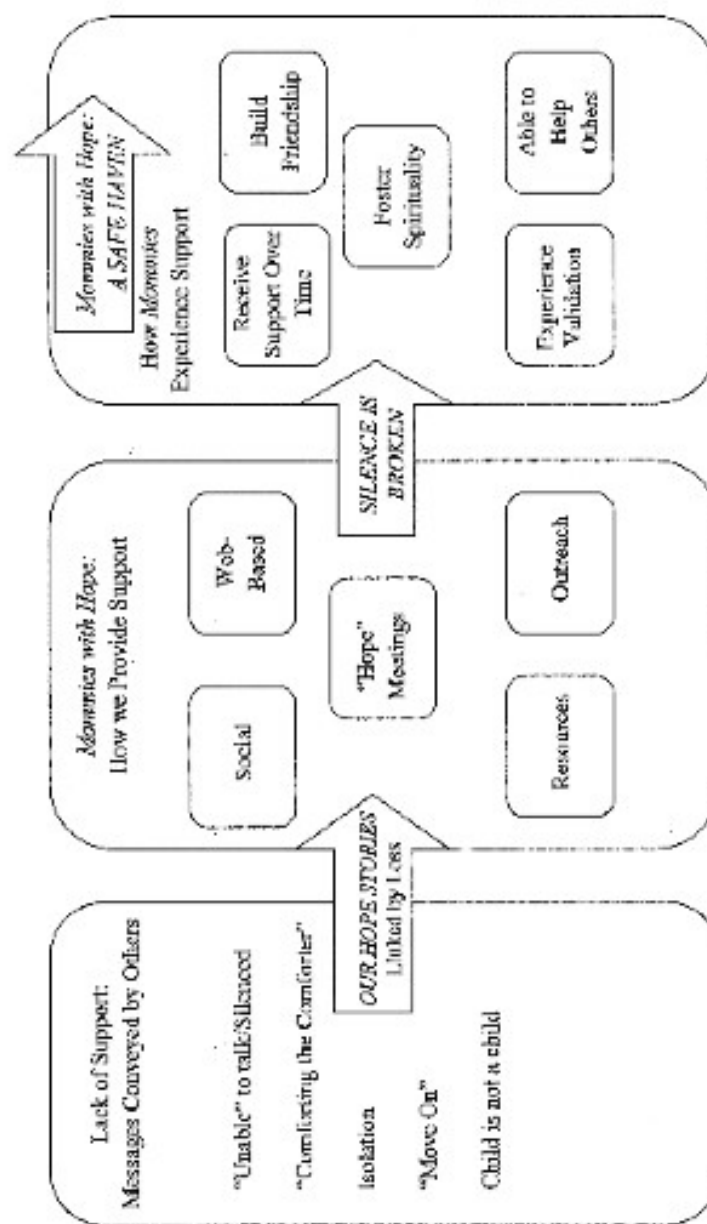




Figure 2. How Women Experience Support through *Mommixer with Hope*

## REFERENCES

- Arnold, J.H., & Gemma, P.B. (1994) *A child dies: A portrait of family grief*. Philadelphia: The Charles Press Publishers.
- Barr, P. (2004). Guilt- and shame-proneness and the grief of perinatal bereavement. *Psychology and Psychotherapy: Theory, Research and Practice*, 77, 493-510.
- Bennet, S.M., Lee, B.S., Litz, B.T., & Maguen, S. (2005). The scope and impact of perinatal loss: Current status and future directions. *Professional Psychology: Research and Practice*, 36(2), 180-187.
- Boss, P. (1999). *Ambiguous loss: Learning to live with unresolved grief*. Cambridge, MA: Harvard University Press.
- Boss, P. (2001). *Family stress management* (2nd ed.). Thousand Oaks, CA: Sage.
- Cacciatore, J. (2008). Effects of support groups on post traumatic stress responses in women experiencing stillbirth. *Omega*, 55(1), 71-90.
- Cacciatore, J., DeFrain, J., & Jones, K.L.C. (2008). When a baby dies: Ambiguity and stillbirth. *Marriage & Family Review*, 44(4), 439-454.
- Cacciatore, J., Schnebly, S., & Froen, F. (2009). The effects of social support on maternal anxiety and depression after the death of a child. *Health and Social Care in the Community*, 17(2), 167-176.
- Cacciatore, J. (2009). The silent birth: A feminist perspective. *Social Work*, 54 (1), 91-95.
- Cait, C. A. (2004). Spiritual and religious transformations in women who were parentally bereaved as adolescents. *Omega*, 49, 163-181.
- Calhoun, B.C., & Hoeldtke, N.J. (1998). The perinatal hospice. *Journal of Biblical Ethics in Medicine*, 9(1), 20-23.

- Calhoun, B.C., Reitman, J.S., & Hoeldtke, N.J. (1997). Perinatal hospice: A response to partial birth abortion for infants with congenital defects. *Issues in Law and Medicine*, 13(2), 125-143.
- Carspecken, P.F. (1996). What is critical qualitative research? In P.F. Carspecken *Critical ethnography in educational research*, (pp.1-22). New York, NY: Routledge.
- Centers for Disease Control and Prevention. (2003). Deaths: Leading causes for 2001. *National vital statistics report*, 52(9), 1-86.
- Condon, J.T. (1993). The assessment of antenatal emotional attachment: Developments of a questionnaire instrument. *British Journal of Medical Psychology*, 66, 167-183.
- Corr, C.A. (1998). Enhancing the concept of disenfranchised grief. *Omega*, 38(1), 1-20.
- Corr, C.A. (2002). Revisiting the concept of disenfranchised grief. In K.Doka (Ed.), *Disenfranchised grief: New directions, challenges, and strategies for practice* (pp.39-60). Champaign, IL: Research Press.
- Crotty, M. (2005). *The foundations of social research: Meaning and perspective in the research process*. London: Sage.
- Davies, D. & Dodd, J. (2002). Perils, pith, and provocation: Qualitative research and the question of rigor. *Qualitative Health Research*, 12(2), 279-289.
- DeSpelder, L.A., & Strickland, A.L. (2009). *The last dance: Encountering death and dying*. New York: McGraw-Hill.
- Detraux, J.J., Gillot-DeVries, Fr., Vanden Eynde, S., Courtois, A., & Desmet, A. (1998). Psychological impact of the announcement of a fetal abnormality on pregnant women and on preprofessionals. *Annals of the New York Academy of Sciences*, 847, 210-219.
- Doka, K.J. (Ed.). (1989). *Disenfranchised grief: Recognizing hidden sorrow*. Lexington,

- MA: Lexington Books.
- Doka, K.J. & Morgan, J.D. (Eds.). (1993). *Death and spirituality*. Amittyville, NY: Baywood.
- Doka, K.J. (Ed.). (2002). *Disenfranchised grief: New directions, challenges, and strategies for practice*. Champaign, IL: Research Press.
- Drake, T.R. (2008). *"It's not fair!" Mothers experiences with perinatal loss upon confirmation of a lethal prenatal diagnosis* (Masters Thesis). Available from Iowa State University Parks Library Special Collection Archives. (ISU 2008 D73).
- Evans, M.I., Soobiecki, M.A., Krivchenia, E.L., Duquette, D.A., Drugan, A., Hume, R.F. Jr., & Johnson, M.P. (1996). Parental decision to terminate/continue following abnormal cytogenetic prenatal diagnosis: "What" is still more important than "when". *American Journal of Medical Genetics*, 61, 353-355.
- Froen, J.F., Arnestad, M., Frey, K., Vege, A., Saugstad, O., & Stray-Pederson, B. (2001). Risk factors for sudden intrauterine unexplained death: Epidemiologic characteristics of signlton cases on Oslo, Norway from 1986 to 1995. *American Journal of Obstetrics and Gynecology*, 184, 694-702.
- Glanz, K., Rimer, B. K., & Lewis, F. M. (2002). *Health behavior and health education: Theory, research and practice* (pp.190-198). San Francisco: Wiley & Sons.
- Gross, D. (2008). *Infancy: Development from birth to age 3*. Boston: Pearson.
- Harris, D. (2009). Oppression of the bereaved: A critical analysis of grief in western society. *Omega*, 60(3), 241-253.
- Harvey, J., Moyle, W., & Creedy, D. (2001). Women's experience of early miscarriage: A phenomenological study. *Australian Journal of Advanced Nursing*, 19(1), 8-14.

- Hebert, M.P. (1998). Perinatal bereavement in its cultural context. *Death Studies*, 22, 61-78.
- Hoeldtke, N.J. & Calhoun, B.C. (2001). Perinatal hospice. *American Journal of Obstetrics and Gynecology*, 185(3), 525-529.
- Howard, E.D. (2006). Family-centered care in the context of fetal abnormality. *Journal of Perinatal and Neonatal Nursing*, 20 (3), 237-242.
- Hutti, M.H. (2004). Social and professional support needs of families after perinatal loss. *Journal of Obstetric, Gynecologic, and Neonatal Nursing*, 34(5), 630-638.
- Kavanaugh, K., Trier, D., & Korzec, M. (2004). Social support following perinatal loss. *Journal of Family Nursing*, 10(1), 70-92.
- Kazak, A.E., & Noll, R. B. (2004). Child death from pediatric illness: Conceptualizing intervention from a family systems and public health perspective. *Professional Psychology: Research and Practice*, 35(3), 219-226.
- Keefe-Cooperman, K. (2005). A comparison of grief as related to miscarriage and termination for fetal abnormality. *Omega*, 50(4), 281-300.
- Kemp, V. H., & Page, C. K. (1987). Maternal prenatal attachment in normal and high-risk pregnancies, *Journal of Obstetrics, Gynecological and Neonatal Nursing*, 16(3), 195-206.
- Kinchloe, L.J., & McLaren, P. (2000). Rethinking critical theory and qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (2<sup>nd</sup> ed., pp. 279-313). Thousand Oaks, CA: Sage.
- Kish, C.P., & Holder, L.M. (1996). Helping say goodbye: Merging clinical scholarship with community service. *Holistic Nursing Practice*, 10(3), 74-83.
- Klass, D. (1999). *The spiritual lives of bereaved parents*. Philadelphia: Brunner/Mazel.

- Korenromp, M.J., Chistiaens, G.C.M.L., Van Den Bout, J., Mulder, E.J.H., Hunfeld, J.A.M., Bilardo, C.M., et al. (2005). Long-term psychological consequences of pregnancy termination for fetal abnormality: A cross-sectional study. *Prenatal Diagnosis*, 25, 253-260.
- Korenromp, M.J., Page-Christiaens, G.C.M.L., Van Den Bout, J., Mulder, E.J.H., Hunfeld, J.A.M., Bilardo, C.M., et al. (2005). Psychological consequences of termination of pregnancy for fetal anomaly: Similarities and differences between partners. *Prenatal Diagnosis*, 25, 1226-1233.
- Kubler-Ross, E. (1969). *On death and dying*. New York: Macmillan.
- Lang, A, Goulet, C., & Amsel, R. (2004). Explanatory model of health in bereaved parents post-fetal/infant death. *International Journal of Nursing Studies*, 41, 869-880.
- Logsdon, M. C. (2000). *Social support in pregnant and postpartum women [Monograph]*. Washington, DC: Association of Women's Health, Obstetric and Neonatal Nurses.
- Lundqvist, A., Nilstun, T., & Dykes, A.K. (2002). Experiencing neonatal death: and ambivalent transition into motherhood. *Pediatric Nursing*, 28(6), 621-627.
- Madison, S. D. (2005). *Critical ethnography: Method, ethics, and performance*. Thousand Oaks, CA: Sage.
- Malacrida, C.A. (1997). Perinatal death: Helping parents find their way. *Journal of Family Nursing*, 3 (2), 130-148.
- Marrone, R. (1999). Dying, mourning, and spirituality: A psychological perspective. *Death Studies*, 23, 495-519.
- O'Leary, J. & Thorwick, C. (2005). Fathers' perspectives during pregnancy, postperinatal loss. *Journal of Obstetric, Gynecologic, and Neonatal Nursing*, 35(1), 78-86.

- O'Neill, B. (1998). A father's grief: Dealing with stillbirth. *Nursing Forum*, 33(4), 33.
- O'Reilly, K. (2005). *Ethnographic methods*. London: Routledge.
- Pesek, E.M. (2002). The role of ritual in the treatment of disenfranchised grief. In Doka, K.J. (Ed.). *Disenfranchised grief: New directions, challenges, and strategies for practice*. (pp. 135-149). Champaign, IL: Research Press.
- Prasad, P. (2005). *Crafting qualitative research: Working in the postpositivist traditions*. Armonk, NY: M.E. Sharpe.
- Rando, T.A., 1986. *Parental Loss of a Child*. Champaign, IL: Research Press Company.
- Rando, T. A. (1995). Grief and Mourning: Accommodating to Loss. In H. Wlass & R. Neimeyer (Eds.), *Dying: Facing the Facts*. (pp. 211-241.). (3<sup>rd</sup> ed). New York: Taylor & Francis Publishers.
- Redlinger-Grosse, K., Bernhardt, B.A., Berg, K., Muenke, M. & Biesecker, B.B. (2002). The decision to continue: The experiences and needs of parents who receive a prenatal diagnosis of holoprosencephaly. *American Journal of Medical Genetics*, 112, 369-378.
- Rhigetti, P.L., Dell'Avanzo, M., Grigio, M. & Nicolini, U. (2005). Maternal/paternal antenatal attachment and fourth-dimensional ultrasound technique: A preliminary report. *British Journal of Psychology*, 96, 129-137.
- Robinson, L. C. , 2003-08-16 "A Call For Visual Ethnography" *Paper presented at the annual meeting of the American Sociological Association, Atlanta Hilton Hotel, Atlanta, GA Online <.PDF>*. 2009-03-05 from [http://www.allacademic.com/meta/p107431\\_index.html](http://www.allacademic.com/meta/p107431_index.html)
- Robinson, M., Baker, L. & Nackerud, L. (1999). The relationship of attachment theory and

- perinatal loss. *Death Studies*, 23(3), 257-270.
- Romesberg, T.L. (2004). Understanding grief: A component of neonatal palliative care. *Journal of Hospice and Palliative Nursing*, 6(3), 161-170.
- Salisbury, A., Law, K., LaGasse, L., & Lester, B. (2003). Maternal-fetal attachment. *Journal of the American Medical Association*, 289(13), 1701.
- Sandelowski, M., & Barroso, J. (2004). The travesty of choosing after positive prenatal diagnosis. *Journal of Obstetric, Gynecologic, and Neonatal Nursing*, 34, 307-318.
- St John, A., Cooke, M., & Goopy, S. (2006). Shrouds of silence: Three women's stories of prenatal loss. *Australian Journal of Advanced Nursing*, 23(3), 8-12.
- Sumner, L.H., Kavanaugh, K., & Moro, T. (2006). Extending palliative care into pregnancy and the immediate newborn period: State of the practice of perinatal palliative care. *Journal of Perinatal and Neonatal Nursing*, 20(1), 113-116.
- Tedeschi, R.G., & Calhoun, L.G. (2004). *Helping bereaved parents: A clinician's guide*. New York: Brunner-Routledge.
- Tedeschi, R.G. & Calhoun, L.G. (2006). Time of change? The spiritual challenges of bereavement and loss. *Omega*, 53 (1-2), 105-116.
- Thomas, J. (1993). *Doing critical ethnography*. Newbury Park, CA: Sage.
- Toedter, L.J., Lasker, J.N., & Janssen, H.J.E.M. (2001). International comparison of studies using the perinatal grief scale: A decade of research on pregnancy loss. *Death Studies*, 25, 205-228.
- Uren, T.H., & Wastell, C.A. (2002). Attachment and meaning-making in perinatal bereavement. *Death Studies*, 26, 279-308.
- Vance, J.C., Boyle, F.M., Najman, J.M., & Thearle, M.J. (2002). Couple distress after sudden



- infant or perinatal death: A 30-month follow up. *Journal of Pediatric Child Health*, 38, 368-372.
- Vance, J.C., Najman, J.M., Thearle, M.J., Embelton, G., Foster, W.J., & Boyle, F.M. (1995). Psychological changes in parents eight months after the loss of an infant from stillbirth, neonatal death, or sudden infant death syndrome-a longitudinal study. *Pediatrics*, 96, 933-939.
- Walsh, K., King, M., Jones, L., Tookman, A., & Blizard, R. (2002). Spiritual beliefs may affect outcome of bereavement: Prospective study. *British Medical Journal*, 324, 1551.
- Wallerstedt, C., Lilley, M., & Baldwin, K. (2003). Interconceptual counseling after perinatal and infant loss. *Journal of Obstetric, Gynecologic, and Neonatal Nursing*, 32, 533-542.
- Wing, D.G., Clance, P.R., Burge-Callaway, K., & Armistad, L. (2001). Understanding gender differences in bereavement following the death of an infant: Implications for treatment. *Psychotherapy: Theory, Research, Practice, Training*, 38(1), 60-73.
- Worden, W. J. (2002). *Grief Counseling and Grief Therapy: A Handbook for the Mental Health Practitioner*, 3<sup>rd</sup> ed. New York: Springer.
- Wortmann, J.H. & Park, C.L. (2008). Religion an spirituality in adjustment following bereavement: An integrative review. *Death Studies*, 32, 703-736.
- Worth, N.J. (1997). Becoming a father to a stillborn child. *Clinical Nursing Research*, 6(1), 71-90.
- Zlotogora, J. (2002). Parental decisions to abort or continue a pregnancy with an abnormal finding after an invasive prenatal test. *Prenatal Diagnosis*, 22, 1102-1106.

Znoj, H.J., & Keller, D. (2002). Mourning parents: Considering safeguards and their relation to health. *Death Studies*, 26, 545-565.

## BIOGRAPHICAL SKETCH

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